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[1] To learn more: https://prolepsis.eu/

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EXECUTIVE SUMMARY OF THE OUTCOMES OF THE FOCUS GROUPS

Background and methodology

- In the period between January to May 2020, 8 focus groups (FGs) were organized by the members of the Prolepsis partnership to gain an insight into informal carers' knowledge on Breast Cancer (BC) and their perceptions on educational and training opportunities and barriers in assuming preventive behaviours.
- Five focus groups consisted of informal carers and 3 of health professionals were organized in Italy, Portugal and Cyprus. More specifically, 26 informal cares (aged 57+) participated and 18 health professionals (aged 35 +).
- Each partner was responsible to organize the focus groups in their country; however, all followed the research protocol prepared by the CUT team. All partners analyzed the data that emerged from the discussions while the final analysis and data synthesis was performed by the CUT team. Results of the FGs were analyzed manually adopting the framework analysis technique (Krueger & Casey, 20014; Rabiee, 2004), a case and theme-based approach that reduces data through summarization and synthesis using a matrix. This method helped to order data, allowing the researchers to analyze them both by case (i.e. the carer's perspective) and by theme.

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

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.

"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)

"I fully believe in screening. I go to the screening every two years, I am called by the screening services." (P6 POR)

'The earlier the diagnosis, the better. I think people today are also more aware of this and in fact WHO has been warning. There is no one who is not afraid of this disease or who has not heard of it' (P4 POR)

Attitudes towards Breast Cancer

Most of the participants are frightened about the issue of breast cancer, but this fear translates into different preventive modalities. For example some of the participants' comments show an attitude of avoidance out of fear; or driven by fear, some others not perceiving themselves at risk or having an attitude towards simply carrying out the strictly necessary practices.

'Prevention is very important…to prevent the worst' (P 2 CY)

Attitudes towards mammography screening

Participants' attitudes towards preventing practices are linked with knowledge, beliefs and perceptions. Some participants avoid this practice, devaluing its benefits and trusting (and assuming) that their health is well. Fear was a consistent theme that arise from the lack of knowledge about the examination procedure.

"Yes, this is a factor" (feels safe with ultrasound and mammography that's why avoid breast self-exam) (P 10 CY)

"I've never been worried about it or even wanted to think about it (…) If I have nothing, what am I thinking about? I already have so much to think about, not to think about one more (…) I don't prevent myself from anything" (P3 POR)

Beliefs of informal carers about the possibility to became ill from BC

Participants feel that they are not particularly at risk of being diagnosed with breast cancer. Consequently, the beliefs developed are consistent with the style of prevention they have adopted: everyone is aware that the screenings can be useful to prevent breast cancer, but there is a gap between the perception of the danger and the implementation of preventive practices.

Identification of the Motivational and Barriers Factors that influence the preventive practices of informal carers

Barriers Factors

Several issues emerged from the participants' focus groups (CY, IT, POR) on the barriers that influence the preventive practices:

- Lack of knowledge and skills to perform BSE
- Devalued Breast self examination
- The perception of being free from breast cancer
- Discomfort of the procedure (mammograpfy, BSE)
- Fear of complications from the procedure – A stressful Procecure (i.e. mammography)
- Fear of suffering from the disease

- Fear of getting ill (no longer being able to take care of your loved one)
- Feelings of guilt in dedicating time for oneself and not to the partner.
- Lack of time to think and perform Breast self-examination practices due to their caregiver role
- Difficulties going to the hospital/health center due to the caregiving duties,
- Forgetting/failing to practice a routine of health prevention.

Motivational factors

Several issues emerged from the participants' focus groups(CY, IT, POR) on the motivational factors that influence the preventive practices:

- Motivation drawn from (past) personal experiences and the experiences of other people who died from cancer
- Fear of the disease
- Significant others
- Perceived responsibility (as an informal carer) towards her loved ones and their family
- Health care professionals
- Campaigns

How their caregiving' role influences their lives

- Changed their life on many different levels (i.e. psychological, emotional and social and physical level).
- Feeling guilty, anger, nervous, loneliness, depression, anxiety, tiredness and exhaustion and fear of losing the person they care for.
- Find some positive aspects for their life, like changing priorities and satisfaction offering care to the other person.
- Feeling more responsible
- Postpone their own appointments
- Dependence on other people

Technology Preferences

The participants mention to be familiar with mobile applications and are interested with applications aimed at preventing disease. According to the participants, some elements should be present in an application for the prevention of breast cancer:

- Video with guidelines
- Supporting forum groups (with health professionals and informal carers)
- Reminders for their appointments
- Chat with self-mutual help groups for informal carers to share prevention path together

- Simple and direct clinical help: humanization of the medical-health service,
- Focus on global health: including elements also on the nutritional side (eg diets / healthy recipes that give insights on the preparation of meals) fitness tips, such as short daily workouts, meditation / mindfulness exercises.
- Stories of people who tell their experience with the disease and how they managed their health, from a physical and psychological point of view.
- Meetings with experts on this topic

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

- The issue of psychological barriers is therefore closely linked to the fear that informal carers can have in undergoing examinations.
- Fear of getting ill and suffering - getting ill would no longer allow them to take care of their loved one.
- The fear is linked to the cancer disease - fear of dying
- A sense of responsibility for caring for their loved one, which therefore takes them further away from prevention
- Lack of knowledge (lifestyle changes/they do not know how to do BSE)
- Lack of time
- Taboo/shame

How the caregiving role influences their habits for breast cancer prevention according to health professional participants

- The experience of caring for a loved one diagnosed with breast cancer is a powerful influential event in the informal carers 's life, in a negative and in a positive way.
- Due to their commitment to care, do not adhere to preventive practices and exams:
    - lack of time due to many responsibilities and
    - fear of the cancer disease (e.g. fear of being diagnosed with cancer)
- Because of their care experience, are meticulous in following the prevention practices:
    - responsibility towards the person they care for and own family
    - the high risk to get cancer

Educational priorities that should be set in a breast cancer education program

- The educational part should focus mainly on **the motivational, emotional side**

- Offer **reliable information** on primary prevention**,** breast cancer (e.g. treatment) and **lifestyle changes** (e.g. physical exercise, healthy diet, losing weight)
- Informal Carers must be motivated to engage in prevention by adhering to practices in a positive sense:
  - Reminding them the importance of being healthy both physically and psychologically, in order be able to take care of her loved one.
  - Teaching them how to manage their time also giving priority to themselves, as this will make them feel better about themselves and others. In conjunction with this, adherence to preventive practices will allow them to manage their health and being able to continue to be a caregiver.
- To teach them to accept, embrace and manage their emotions (emotional side e.g. emphasis on the negative ones).
- To educate them to express their feeling (good and bad) and not to feel guilty, or emotions such as fear, anger, sadness and helplessness.

What should be included in a breast cancer educational program in order to motivate informal carers to adopt breast cancer prevention behaviours

- Include themes in order to convice informal carers that prevention saves lives and to motivate them to do their screening tests and BSE regularly.
- The importance for their mental and physical health, for their well-being, to dedicate time for themselves, adopting a healthy and consistent lifestyle.
- Changing lifestyle (physical exercise, healthy diet, losing weight) *that can be one factor that can prevent cancer.*
- Information on primary prevention of breast cancer and information on breast cancer disease and its treatment in order to manage the fear of cancer disease
- Activities suggestions and exemplification, at a non-advanced but accessible level.
- Demonstration how the practice of physical activity is also important for mental health, since it contributes to regulating the stress levels and having a moment for themselves.
- Motivational factors for adherence to preventive behaviors against breast cancer: positive survival rates, sharing testimonies of those who were early-detected cancer and were able to recover effectively or simply women who, by regularly do the screening; can be calm because they know they are healthy.
- Use of technology to promote preventative behaviors.

What features are needed for the mobile app in relation to breast cancer prevention

- Simple, realistic, user friendly and with optimistic messages
- Have a network (e.g. such as chats or groups) of informal carers who can relate and thus support each other, sharing fears and doubts.
- Provide Professional help and support to informal carers
- There is a need for humanized contact between professionals and users
- A **motivational and emotional part** that regards adherence to practices, lifestyle, nutrition, meditation, exercise etc.
- Appointment or medical examinations reminders that allow the organization of information in a single application
- Recommendations for a healthier lifestyle, especially in terms of food and physical activity and that prevents diseases
- Positive messages of encouragement and hope
- Information about the functioning of the health system and other elements related to the prevention and treatment of breast cancer that allow, in a simple and interactive way, the clarification of the population
- A good articulation with the work carried out by superior entities so that two different and even confusing sources of information are not revealed.

Barriers for using mobile application

- Resistance to use the technology
- Elderly people not familiar with technology

Table I. Barriers to breast self examination in relation to the role of informal carer (common findings and differences among two groups)

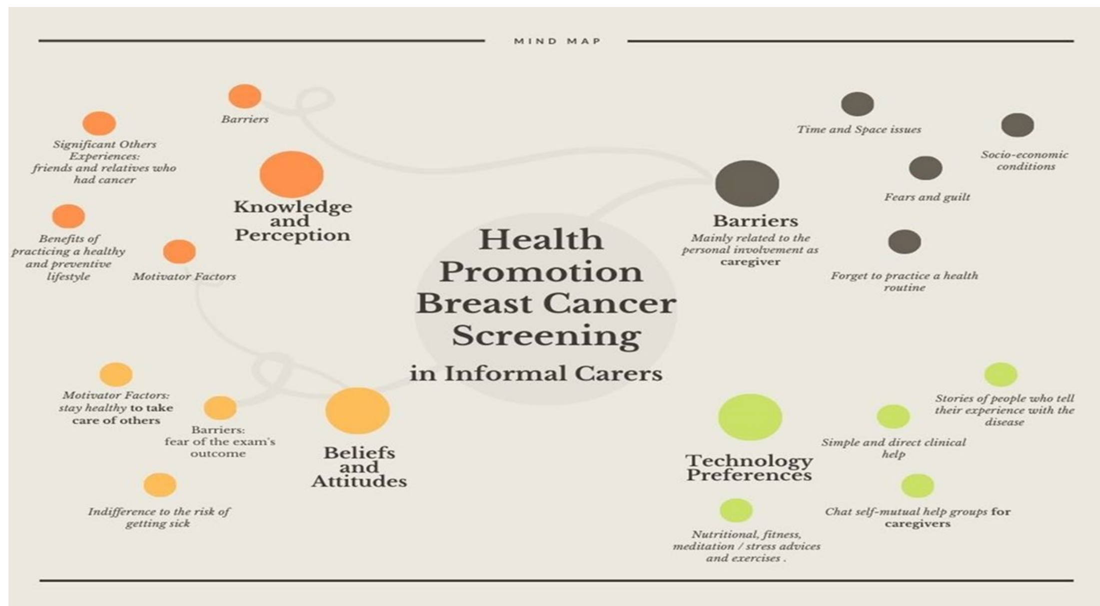
Barriers to breast self examination in relation to the role of informal carer	Informal carers	Health professionals	Common findings
	✓ Devalued Breast self examination ✓ The perception of being free from breast cancer ✓ Discomfort of the procedure (mammography, BSE) ✓ Fear of complications from the procedure – A stressful Procedure (i.e. mammography) ✓ Difficulties going to the hospital/health center due to the caregiving duties, ✓ Forgetting/failing to practice a routine of health prevention. ✓ Due to their commitment to care, do not adhere to preventive practices and exams: ✓ Because of their care experience, are meticulous in following the prevention practices:	✓ The issue of psychological barriers is therefore closely linked to the fear that informal carers can have in undergoing examinations ✓ Taboo/shame	✓ Lack of knowledge and skills to perform BSE ✓ lack of time due to many responsibilities and ✓ fear of the cancer disease (e.g. fear of being diagnosed with cancer) - fear of dying ✓ fear of no longer being able to take care of your loved one) ✓ responsibility towards the person they care for and own family ✓ Lack of time to think and perform Breast self-examination practices due to their caregiver role

	the high risk to get cancer		

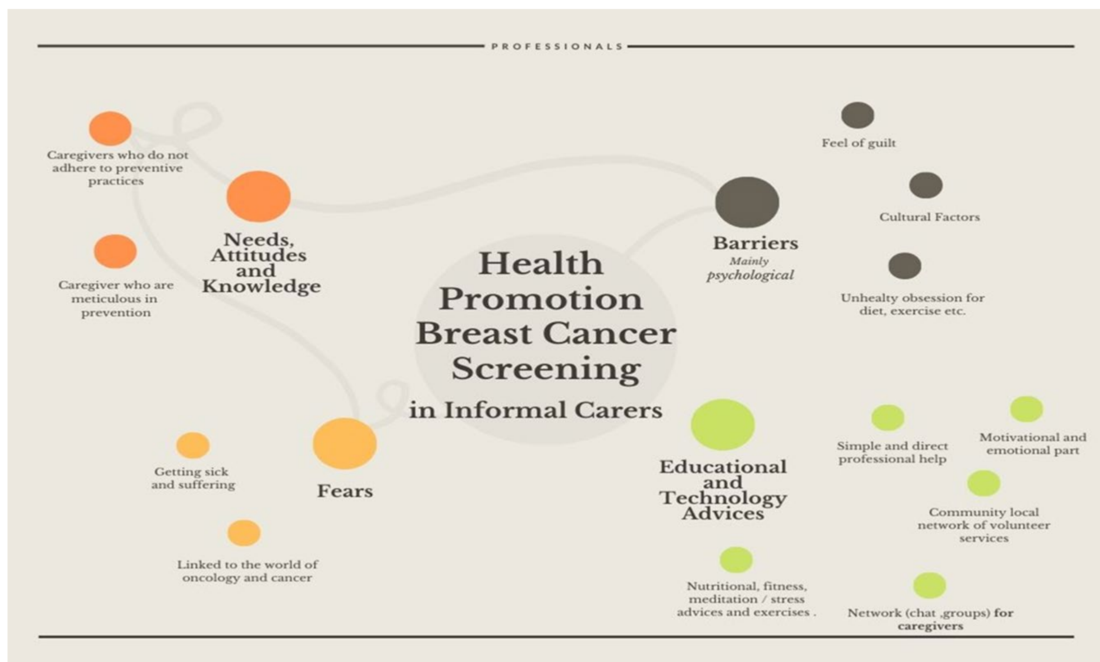
Table II Motivational factors and Barriers that influence informal carers preventive practices (common findings and differences among two groups)

	Informal carers	Health care Professionals	Common findings
Motivations	✓ Fear of the disease ✓ Significant others ✓ Health care professionals ✓ Campaigns	✓ Perception of high risk to get cancer	✓ Experience ✓ Responsibility towards loved ones and family

Informal Carers



Healthcare Professional



INTRODUCTION

PROLEPSIS is a European project funded under the Erasmus+ KA2 programme.

Caregiving 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 carers' 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 (https://ecibc.jrc.ec.europa.eu/recommendations), women's adherence to screenings programmes is relatively poor. The average attendance in the EU was below the standard acceptable level that is 70% (Perry et al. 2016).

The 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 carers 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 carers' knowledge regarding the impact of their prevention avoidance behavior 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 carers to better manage self-care and behaviour change in illness prevention.

• To produce a handbook for educators working with informal and formal education and healthcare professional working with women's health promotion, on how to use the app in health-literacy reinforcement programmes targeting not only informal carers but women's

health in general. The handbook will be 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.

The aim of the first intellectual output of the project is to produce a report aimed to set the scene for the development of educational programme and the App for women caregivers. It will provide new knowledge and attainable heights of insight on relevant stakeholders' (i.e. experts, end-users associations and end-users caregiver) perspectives on educational and training opportunities as well as identifying any barriers in promoting breast cancer prevention. Stakeholders' perceptions have been retrieved in all partners' countries, with the help of the focus group tool. Each partner undertaken focus groups both with informal female caregivers, and with selected professionals, such as: educators, advanced nurse practitioners, medical oncologists, health promotion professionals and representatives from all relevant professional associations and societies (e.g. NGOs active on breast cancer issues).

The aim of the focus groups with caregivers was to facilitate participants to discuss their knowledge of breast cancer and screening guidelines and recommended practices; individual, structural, and cultural barriers to screening; attitudes on mammogram screening, breast cancer experiences (personal or of a significant other), self–rated risk for breast cancer, current state of mobile phone usage habits, including text and picture messaging, needs for mobile based learning applications, readiness for mobile-based learning applications and ideas regarding the most effective content, type and frequency of messages the interventions to promote screening. The aim of the focus groups with professionals was to gather health professional community's opinions and describe their views on the educational priorities about breast cancer and breast cancer prevention including screening (e.g. gaps in knowledge, concerns, and priorities).

THE RESEARCH PROTOCOL

Title: A qualitative exploration of informal caregivers and health care professionals' perspectives on breast cancer and breast cancer screening

Research Team (local)

Each partner decides on this (preferably include persons with experience in focus groups e.g. as moderators, data analysis, bilingual translators).

Background

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 (i.e. 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 and the national health systems throughout Europe follow the European Union's (EU) recommendations for the provision of mammography screening to detect BC in an early stage (https://ecibc.jrc.ec.europa.eu/recommendations), women's adherence to screening programs is relatively poor. The average attendance in the EU was below the standard acceptable level that is 70% (Perry et al., 2016). This can also be attributes 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).

Caregiving of a person with a chronic disease can also be a contributing factor, don't attaining breast cancer information, adopting breast health behaviors and poor screening adherence. It is possible the caregiving role may reduce the amount of time available to engage in preventive health services. Studies show that the majority of caregivers to 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.

Evidence 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). Caregiving has been identified as a significant factor that can lead to poor utilization of heath care services in the early stages of BC (Kinnear et al. 2010). Informal carers 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 carers' impaired health behaviors, such as neglecting their own health care appointments and non-seeking cancer screening tests compared to non-carers (Son et. al., 2007). As nearly two-thirds of informal carers aged over 50 year are women (Carretero et. al., 2012), the burden of caregiving raises concerns regarding women's health including BC prevention. The project aims to develop a mobile phone-based health intervention as a means to enhance preventive health care among informal carers 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).

Behavioural characteristics of informal carers

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 public is 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 suggests 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 carer face additional challenges in engaging in health promotion practices such as BC screening (Kinnear et. al., 2010). Explicitly, studies on carers' 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 non-carers (Burton et. al., 1997).

Aim of study

This project focuses on promoting breast cancer screening. The first part of the project aims to retrieve informal carers' perspectives on the importance of screening for early detection of breast cancer symptoms and the actual practices they adopt in their everyday life.

Objectives are:

- Mapping the needs, attitudes, knowledge believes and perceptions of informal carers on breast cancer screening practices.

- Explore the knowledge and perceptions on educational and training opportunities and barriers in promoting prevention.
- Explore health care professionals' (experts) knowledge and perceptions on educational and training opportunities and barriers in promoting prevention.

Method

Study design

A qualitative approach will be utilized for this study. The focus group method has been selected as a way of collecting qualitative data, but also as a technique for gaining a large amount of data regarding opinions and attitudes in the shortest amount of time. It relies on group processes and encourages interaction between group members, resulting in deeper exploration of the subject under study (Bowling 2014). Focus group, through focused discussions, enable the researchers to study a topic of interest in depth by composing teams (purposively chosen according to the study's aim) in which participants discuss similar experiences and share common characteristics. Participants are encouraged to freely express their feelings, ideas, agreements or disagreements in a non-threatening environment. Furthermore, discussions stimulate memories and facilitate the exchange of ideas and opinions, leading to a more in-depth study of the research topic.

Participants

Three focus groups will be organized, with 6-8 participants in each group. Each partner (Cyprus, Italy, Portugal) will be responsible to recruit the required sample according to the pre-specified criteria and taking into consideration the local conditions (e.g. organisations, NGOs). Two groups will consist of informal carers and a third one of health care professionals. It is assumed that the above process will facilitate discussions and allow a more in-depth investigation of the topic under study.

A convenient purposive sample of informal carers will be invited to participate in the first two groups. The convenient purposive sampling technique will be used so that the desired homogeneity and heterogeneity of the groups are achieved. Homogeneity will be achieved since all participants will fall in the category of being informal caregivers over 55 (Krueger & Casey 2015).

Following analysis of the data from the focus groups with the informal carers, a purposive sample of experts will be invited to participate in the third focus group. The purposive sampling technique will be used so that the desired homogeneity and heterogeneity of the group are achieved. Homogeneity will be achieved since all participants will be persons with a direct

relation to the care of the women who are diagnosed with breast cancer and also heterogeneity since they will be of different age, different experiences and background.

All discussions will be held in the partner's local language.

Inclusion criteria for the informal carers will be:

- Female informal caregivers over 55 involved in the care of a person diagnosed with any chronic disease (cancer, dementia etc.).
- Willingness to participate by completing electronic/or formal application form after being informed.

Inclusion criteria for the health care professionals will be

- Health care professionals: e.g. educators, advance nurse practitioners, medical oncologist, health promotion professionals and representatives from all relevant professional associations and societies (e.g. NGOs active on BC issues)
- People with BC working experience (>2 years).

Data collection

Focus groups with Informal Carers

Each partner country will be responsible of recruiting an experienced person to act as the moderator of the discussions. The moderator will use a semi-structured interview guide during the interviews (Appendix I). A demographic questionnaire will be distributed at the beginning of each focus group (Appendix II). The moderator will start with a general introduction and will proceed to the use of the interview guide in order to initiate and facilitate the discussion:

1. What are your experiences of being an informal caregiver to your loved ones?
2. Do you find that your involvement in patients care somehow, influence your life negatively?
3. Could you tell us a bit more about your experience and feelings as a caregiver and the caregiving journey since the diagnosis until today?

4. Does your person you care for, described life–changing experiences (traumatic*)? How is that affecting you? (*Diagnosis of cancer is considered a type of trauma in the DSM-5 (American Psychiatric Association, 2013).

5. Do you think that habits like smoking, alcohol consumption and unhealthy diet can cause cancer?

6. Are you worried whether there is a risk for you to become ill from breast cancer?

7. What makes you to practice Breast-Self Examination?

8. Are there any barriers related to your caring role, for you to engage in Breast-Self Examination?
9. What is your perspective about mammography screening test?
10. Are there any barriers or worries in relation to screening (in general but with reference to mammography procedure for example)?
11. Are you aware of the benefits of early detection of breast cancer?

Focus groups with healthcare experts

Each partner country will be responsible of recruiting an experienced person to act as the moderator of the discussions. The moderator will use a semi-structured interview based on topics (e.g. educational priorities about BC, areas generating concerns in relation to breast cancer screening) that will be identified from the informal carers focus groups and in combination with the relevant literature The moderator will use a semi-structured interview guide during the interviews (Appendix IV).

A short demographic questionnaire will be distributed at the beginning of each focus group (Appendix III). Each focus group session will be audio-recorded and will be transcribed verbatim by the members of the research team in each partner country. Field notes will be kept during the discussions in order to identify any nonverbal responses (e.g. waves, gestures or other body movements that may show agreement or disagreement against a statement verbally said or demonstration of being uncomfortable to a topic being discussed), will be supplemented at the transcripts.

Data analysis

Analysis will be done with a thematic content analysis of the transcripts, by coding emerged themes into categories related to the aim of the study. More specifically, within each transcript, relevant themes (words, phrases) on the topic under study will be highlighted and then coded under headings (categories). The analysis of the selected data will be centralised by CUT with the use of "Nvivo" software. All participants will send the data translated in English language.

The data analysis results will be sent to all participants. The identified topics in combination with issues identified from the relevant literature will inform the basis of the subsequent focus groups with the healthcare professionals.

Ethical consideration

The study's protocol will be submitted for review at the appropriate authorities according to National Law for ethical approval. Informed written consent for participation in the study will be requested and obtained from all participants. All data will be kept safely with access limited only to the members of the research team and only for the purposes of the present study. All data will be destroyed after the completion of the study (e.g. audio tapes will be erased and transcripts will be destroyed three years after the end of the PROLEPSIS project). Confidentiality will be maintained during the research process and participants will have the right to withdraw at any time.

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FOCUS GROUPS WITH INFORMAL CARERS – OUTCOMES

Informal Caregivers Demographics Report (selected demographic information)

Caregivers were recruited from Cyprus (9), Italy (5) and Portugal (12). The mean age of the caregivers in the three countries was 57,72 (SD 6,88) (Table 1). The highest mean age was recorded in Portugal was 61,73 (5,02) followed by a mean age of 58,60 (8,98) in Italy and 52,33 (SD 3,90) in Cyprus. The highest educational level of the caregivers was recorded in Portugal (i.e. Tertiary Education) followed by higher secondary education (Cyprus + Portugal). In terms of the time that the caregivers have been involved in caregiving, only minor differences were recorded across the three countries. On average the participants were providing care to their loved ones for 11,19 months (SD 8,99) (Italy, Cyprus, Portugal). Significant differences were found in the average amount of hours that caregivers devoted to caring. The highest amount was recorded in Portugal (mean 49,60, SD 65,93), followed by Cyprus (mean 31,27 SD 31,40) and Italy (mean 21,00, SD15,90) (Chart 1).

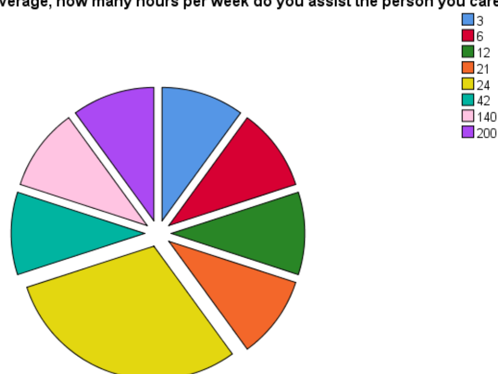


FIGURE 1 CHART 1

The majority of the caregivers in the study (53.8%) were caring for a severely dependent person which reflects the amount of time spent on a weekly basis (Table 2).

Table 2: How dependent is the person you care for? (Italy, Cyprus, Portugal)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Independent	7	26,9	26,9	26,9
	Slightly Dependent –	4	15,4	15,4	42,3

	Moderately Dependent	1	3,8	3,8	46,2
	Severely Dependent	14	53,8	53,8	100,0
	Total	26	100,0	100,0	

There was a consistent finding in the relationship of the caregiver to the person receiving the care. Therefore, the analysis showed that the caregivers provided care primarily to their parents (i.e. caregiver was either son/daughter). The highest level of caregivers providing care to their parents was recorded in Cyprus (n>50%). The mean age of the recipient of the care in the three countries combined was found to be 66,81 (SD 19,98). Chart 2 demonstrates that the majority (64%) of the informal caregivers stated that they complied with the cervix cancer screening guidelines. The same percentage of informal caregivers (64% or n=16) stated that they perform breast self-examination regularly.

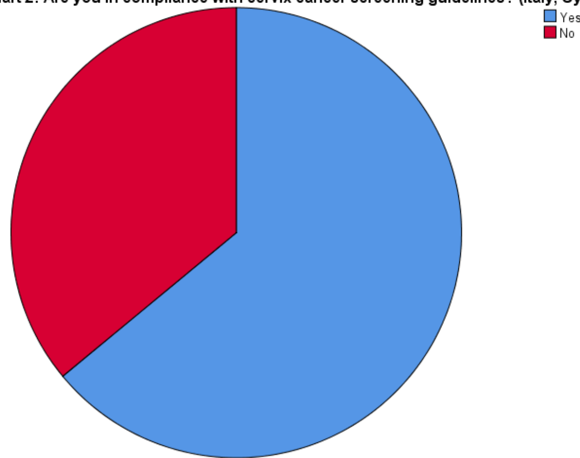


FIGURE 2 CHART 2

Table 1: Descriptive Statistics (Italy, Cyprus, Portugal)

	N	Minimum	Maximum	Mean	Std. Deviation
Age	25	45	68	57,72	6,889
Please specify what is your marital status at present	26	1	4	2,08	1,294
Are you in compliance with cervix cancer screening guidelines?	25	1	2	1,36	,490

Do you perform breast self-exam regularly and as your doctor/health professional recommendations?	25	1	2	1,36	,490
Do you have a specific disease?	25	1	2	1,52	,510
What is your educational level?	21	1	4	2,76	,995
Please indicate your present working situation:	25	0	4	1,80	1,414
What is your relation with the person you care for?	26	1	6	2,58	1,206
How long have you been providing assistance to him/her?	26	2	38	11,19	8,998
On average, how many hours per week do you assist the person you care for?	23	3	200	38,00	48,527
How dependent is the person you care for?	26	1	4	2,85	1,347
Valid N (listwise)	16				

In terms of the impact of caregiving (assessed on 6-point Likert scale with 1 -no impact at all to 5 – extreme impact), the analysis of the research data showed a significant impact across (in the three countries combined) health issues, psychological issues, cognitive issues and the feeling of being isolated. The psychological and cognitive issues were reported by the caregivers as being greatly affected by the caregiving responsibilities (Tables 3 and 4 respectively).

Table 3: Psychological impact (ex. Feelings of depression, anxiety, loneliness, guilty, stress…)(Italy, Cyprus, Portugal)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	3	8	30,8	30,8	30,8

	4	11	42,3	42,3	73,1
	5	7	26,9	26,9	100,0
	Total	26	100,0	100,0	

Table 4: Cognitive impact (ex. memory, attention)(Italy, Cyprus, Portugal)					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	2	7,7	7,7	7,7
	3	9	34,6	34,6	42,3
	4	11	42,3	42,3	84,6
	5	4	15,4	15,4	100,0
	Total	26	100,0	100,0	

The health impact on the informal caregivers was reported by the majority (n=9) as being low to average (n=17)(Chart 3). Finally the isolation impact on the caregivers was assessed as being average to extreme (≥3) by the majority of the caregivers (n=24).

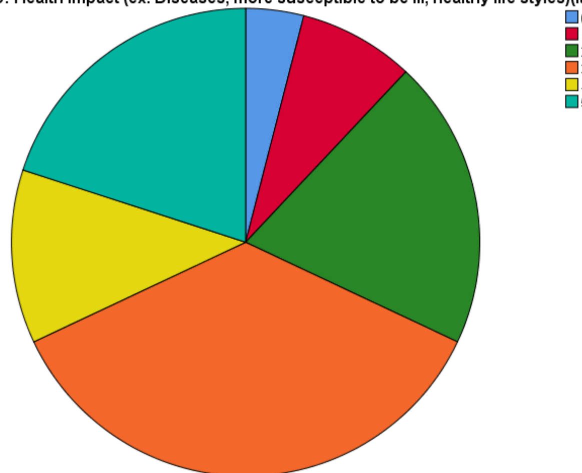


FIGURE 3 - CHART 3

SECTION 1: MAPPING THE NEEDS, KNOWLEDGE, BELIEFS AND PERCEPTIONS OF INFORMAL CARERS

Knowledge and Perceptions

All responders (CY, IT, POR) reported to have knowledge of BC prevention practices including self-examination and clinical examination. They recognized the value of screening tests such as mammography, but not all of them follow the prevention programs. Especially most of them, they do not perform BSE and compared to mammography they considered its value to be limited. Greek-Cypriots and Portuguese women keep a positive attitude and an optimistic way of thinking about the diagnosis of breast cancer.

"Let's find it at the initial stage… if we have something!" (P 4 CY)

"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)

"Prevention to make it easier to treat. Do early diagnosis…like my mother, she did a surgery and her therapy and she was fine" (P 8 CY)

"Yes we do our test, one year Pap test and mammography test, and the next year ultrasound and breast- self-examination." (P7 CY)

'I am not afraid to being diagnosed with cancer' (P4 CY)

'The earlier the diagnosis, the better. I think people today are also more aware of this and in fact WHO has been warning. There is no one who is not afraid of this disease or who has not heard of it' (P4 POR)

"I fully believe in screening. I go to the screening every two years, I am called by the screening services." (P6 POR)

"I think that we are moving towards it (referring to breast cancer) to be eradicated" (P5 POR)

Motivational factors and barriers

Several issues emerged from the participants' focus groups (CY, IT, POR) on the motivational factors and barriers that influence the preventive practices.

CYPRUS

Barriers factors

Lack of knowledge and skills to perform BSE

“No, I don’t understand what I am going to feel palpating my breast” (P1 CY)

“I do not understand if something is abnormal when I do BSE” (P 1 CY)

‘The only think I don’t’ do on my own is BSE, I don’t know how to do it.....” (P5 CY)

Devalued BSE

“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)

“Honestly I do not perform BSE often, I feel safe because I am doing my mammography and ultrasound tests. Keeps me safe” (P10 CY)

Fear of suffering from the disease

“I often do the appropriate diagnostic examinations because I am afraid of this disease. My concern is that I have to constantly to watch for it.” (P 3 CY)

“…maybe it scares me” (P10 CY)

Fear of complications from the procedure - A Stressful Procedure (i.e. mammography)

‘…is it safe to do every year mammography… I am afraid of radiology!’ (P 4 CY)

“If I am thinking of this (to get sick from breast cancer) all the time…I think this would be a problem. It will cause me anxiety’ (P 10 CY)

Financial barriers - National Programme Screening tests

“They don't do it to us. The national program offers mammography test every second year)” (P7 CY)

The national program offers mammography test every second year)” (P9 CY)

Lack of time due to their caregiver role

“I do not have enough time to have a shower and …I will do a BSE!’ (P 2 CY)

Age-related misconceptions on prevention

‘In general, I am a careless person. I am only 46 years old- I am feeling young. ‘I am 46, when I am 56 maybe I will do the test every year…’ ‘Mammography helps the prevention of breast cancer’ (P 4 CY)

The perception of being free from breast cancer

“Can I tell you why I'm not doing this (refers to BSE)? Because I keep in mind that I may not having something!” (P2 CY)

'Ok because I already had thyroid cancer, my mom has uterine cancer, we're worrying of other types of cancers than breast cancer!" (P 6 CY)

Motivation factors

Motivation drawn from personal experience and the experiences of other people who died from cancer

"(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)

"Because I lost my sister in law, I am going every year to do mammography…it is a constant reminder" (P 5 CY)

"I think it is treatable if you diagnosed it in the early stages, like my mother. She did the surgery, chemotherapy, radiation therapy, it was fine afterwards. She managed the breast cancer…" (P 8 CY)

Fear of getting ill (no longer being able to take care of your loved one)

"Yes, I do my exams! When I feel something on me, I run to the doctor … let's just say I have to be strong if I have something wrong with me who's is going to care my husband.?…." (P1 CY)

ITALY

Barriers factors

Fear of the results/suffering from the disease

"I'm scared to receive bad news about illness" (P1 IT)

"I do not go to screening appointments. Maybe I could overcome the fear if someone came with me" (P1 IT)

"It scares me because I knew people who got cancer" (P2 IT)

"It scares me, so I do not do it by myself" (P3 IT)

Fear of getting ill (no longer being able to take care of your loved one)

'I'm a caregiver and I can't get ill so, even if it's a stupid reasoning, I prefer not to be aware of potential diseases' (P1 IT)

"Positively, I need to take care of myself in order to take care of others too" (P4 IT)

Motivation factors

Motivation drawn from personal experience and the experiences of close people who died from cancer.

"Yes, a lot of my relatives got cancer. This made me to go to screening appointments regularly." (P2 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)

"Yes, my grandparents and my father got cancer, so I regularly do checkups." (P3 IT)

"I took care of a friend who had cancer; it made me more afraid of this disease." (P4 IT)

Perceived responsibility (as an informal carer) towards her loved ones

"I do it, because if I get sick, who is going to take care of my family?" (P4 IT)

"Positively, I need to take care of myself in order to take care of others too." (P4 IT)

PORTUGAL

Barrier factors

Fear of the results/suffering from the disease

'It is not that people do not want to be tested, they are afraid. What we all feel is fear'. (P4 POR)

"I have, unfortunately, a sister-in-law who had to remove one breast (mastectomy), five or six years ago and I have a friend who just now had to remove a breast, she has horrible pains" (P6 POR)

Fear of complications from the procedure (mammography)

'I am also very afraid of radiation' (P1 POR)

'...radiation will damage other organs, causing osteoporosis, etc' (P4 POR)

Discomfort of the procedure (mammography, BSE)

"Mammography-is a bit painful procedure" (P1 POR)

"It's uncomfortable to do mammography I don't really like doing it" (P2 POR)

'I think it makes me sick to squeeze the breast (refers to mammography test), of course if the doctor asks, I will do it. Only I complain a lot when I'm taking the exam' (P3 POR)

Ignorance, prejudice with the body and lack of knowledge

"I think that the ignorance of the situation contributes but there are also prejudices in relation to the body, many times. Today we think it does not exist. However, I think it still exists. And therefore, it is also this prejudice that sometimes prevents people from having these tests" (P6 POR)

"In my case, it's the lack of knowledge" (P7 POR)

Motivation factors

Motivation drawn from personal experience and the experiences of close people who died from cancer.

'When we have someone in the family who has it (refers to breast cancer), we are more aware to this situation' (P4 POR)

'I used to do palpation but now I do it more often, after I had a problem and the age is already advancing' (P6 POR)

"I have, unfortunately, a sister-in-law who had to remove one, five or six years ago and I have a friend who just now had to remove a breast, she has horrible pains" (P6 POR)

"I am to avoid and detect early if something comes up, since I have already removed a lump from the breast and I must always be alert" (P2 POR)

"When, the first time, calcifications were detected, I was so scared. But it was normal for me to go to the doctor and get tested. There, it started there. From there, it is a routine; it is a normal thing, for me, to watch, to go to the doctor. And my motivation ... Of course, I am afraid, it is evident…" (P6 POR)

Knowledge about performance of the Breast Self-Examination (BSE)

Participants reported that **they do not perform BSE**, because either **they do not know the right way to do it or feeling discomfort when approaching the subject** (feeling uncomfortable as a practice *per se or feeling fear (IT)*). Other participants claimed that they often forget to perform BSE or not being able to remember how to practice it. These factors have contributed to abandon the practice itself. In the palpation attempt, **they are not aware of an abnormal finding or what they need to feel.** Most of them feel safe with mammography

and ultrasound screening tests (i.e. provided by national programs), because of that, they consider **BSE less important (under estimated) (CY, IT)**.

In fact, some others participants mentioned that they know how to do BSE (CY, IT, POR) and that **health professional trained them or motivated/guided them.** Moreover, the frequency of performing BSE varied from once a month to two or three times a month.

However, participants who have **a family history of breast cancer consider BSE to perform it on a systematic basis- motivate them to pay attention to the prevention or early detection of breast cancer.** They incorporated BSE into their daily routine.

Regarding the question when participants think they should consult a health professional, participant's answers vary between regular consultations and consultations only when an abnormality is detected.

Lack of knowledge and skills to perform BSE

"No, I don't understand what I am going to feel palpating my breast" (P1 CY)

"I do not understand if something is abnormal when I do BSE" (P 1 CY)

'The only think I don't' do on my own is BSE, I don't know how to do it….." (P5 CY)

"I think that the ignorance of the situation contributes but there are also prejudices in relation to the body, many times. Today we think it does not exist. However, I think it still exists. And therefore, it is also this prejudice that sometimes prevents people from having these tests" (P6 POR)

"In my case, it's the lack of knowledge" (P7 POR)

Perceived importance of BSE

"(Yes)… after my mom's breast cancer but I have a mastopathy as well that I have to watch it' (P 3 CY)

I don't have this on my mind! I don't worry about that!! … but yes!!! we have to do it" (P 4 CY)

"Do you know what that means? It's becoming a way of life…having a family history of cancer!" (P 7 CY)

'Yes, it is important' (Ps 1, 2,3,4,5 IT)

"The sooner we know, the better it is for us to eradicate" (P7 POR)

'According to many testimonies, it was in the breast self-examination that they discovered (…) they even say that they do the second screening exam every 2 - 3 years but that if the person notices something in the meantime, it should be reevaluated, that's why it should be done palpation' (P4 POR)

"I think it is essential that we get to know our body" (P6 POR)

Frequency BSE

"I am not doing BSE' '...I don't understand it or why I should do it' (P1, 2 CY)
"I do breast self-examination or I often palpate my breast because I am afraid of this disease. My concern is that I have to watch it" (P 3 CY)
-"(...) not systematically, sometimes in the bathroom I can look, but just like that, not on a systematic basis" (P 6 CY)
"Every month... In the past it was just when I finished my menstruation...now, not having menstruation any more, I do my check when I go the bathroom" (P 7 CY)
"I palpate my breast to see if it's ok but not very often...I do not have this in my mind all the time" (P9 CY)
'"Not often... I feel safe because I do ultrasound and mammography' (P10 CY)
"I don't do it" (P 1 IT)
"I don't do it" (P 2 IT)
"It scares me, so I do not do it by myself" (P 3 IT)
"The sooner we know, the better it is for us to eradicate" (P7 POR)
"Just once a month" (P2 POR)
"Once a month" (P5 POR)
"I do it often. I cannot say that I do it every eight days and that, but no. I do it often. Because I want to be fine (...) More than once a month, two, three times" (P6 POR)
"I never perform a breast self-examination" (P4 POR)
"No, if I don't feel anything" (P4 POR)
"I don't know how to do it. (...) I've tried it (...) I just know that it is putting my hand under the armpit and seeing if there are any chats there" [laughs] (P7 POR)
'I do not know if people do it all the same way. I think it is at a time when I am soapy that it is easier to pass the hand' (P4 POR)
'I also usually do it. And when I'm nervous, after bathing and when I have time, I lie down a little and do it more calmly. I will palpate one side or the other to see if there are differences' (P1 POR)
'It is easier at bath time' (P5 POR)
'I do the exams, mammograms that the doctor tells me to do but then, in my daily life, I don't care. I never got into the habit' (P3 POR)
'I usually do, with a certain frequency. Sometimes in the bathroom, sometimes when I'm lying (...) every week' (P2 POR)
'I honestly I don't say that I do it 2 to 3 times a week, but I do it quite often' (P4 POR)

'…to have the routine when I take a bath 2-3 times a week but I never felt anything' (P5 POR)
"I think so, more or less, it may not be with the rigor of a nurse, a doctor. But we have to put our hands behind our heads, raise our arms, feel under an armpit, on our chest, and see if nothing really different appears" (P10 POR)
'Self-breast examination makes me uncomfortable as a practice per se, therefore I don't do it' (P3 IT)
'No, I don't do breast self-examination. If I suspect to have some disease because I do not feel well, I go to the doctor. I try not to dwell on it too much because, knowing myself, then I would think to have all the disease! So since fortunately there was this possibility of screening, when they call me, I go, before I went on my own anyway. Always with terror on me, but I force myself to go. I would have more difficulty going spontaneously in these cases, so the fact that there is a schedule with appointments helps me' (P5 IT)

Consulting a health professional

When participants been asked about the importance of consulting a health professional, the answers varied between regular (i.e. scheduled) consultations (National Public Screening Program) and consultations only when an abnormality is detected.

"I believe that when woman, give birth to her first child, every year she has to do the test, in her entire life. I remember 38 years ago when I gave birth to my first son, my gynecologist told me from now on that every year you will come for a PAP test …" (P 1 CY)
'I believe that when the period stops (refers to menstruation), women becomes more vulnerable that's why they have to do systematically examinations' (P2 CY)
"Because I know a lot of people who had a period (refers to menstruation) and suffered from various things, normally they have to start very early!" (P5 CY)
"Anyway, as soon as we feel something, our mind always thinking the worst scenarios. Let's run to the doctor" (P9 CY)
"Ok If I palpate a tumour, I will be shocked and then I visit the doctor immediately" (P 10 CY)
"I always go to appointments made by the public health care system for the screening of breast cancer' (P2 IT)
"I take advantage of the public health care system screening program, when I am called to the appointments for breast cancer screening, I go" (P3 IT)
"I regularly go to medical appointments in order to do checkups. Specifically, I see a gynecologist who is also oncologist" (P4 IT)
'A swollen node, a breast lump' (P2 POR)
'Feel pain or discomfort, anything that caught the attention' (P4 POR)

“I've been doing this since I was 35. It used to be every three months” (P3 POR)

Perceptions

Do you believe that screening could help?

All Participants reported that doing screening tests would help with early prevention and early intervention of breast cancer.

“The fact that I am doing my mammography and ultrasound tests keep me feeling safe’ (P10 CY)

“Could help on prevention” (Ps 2, 4, 1, CY)

“Let's find the worst soon!” (P2 CY)

“Let's find it at the initial stage… if we have something!” (P 4 CY)

“Definitely!” (P 9 CY)

“Surely when you find something you will try to manage it?” (P9 CY)

“Yes, prevention is easier to manage a disease better’ (P 10 CY)

‘Yes screening could help’ (P1, 2,3,4,5 IT)

‘Sometimes, they can be calcifications that are not palpable and that are seen on mammography or ultrasound’ (P2 POR)

“I fully believe in screening. I go to the screening every two years, I am called by the screening services” (P6 POR)

Special themes: Specifically, they stated that they do regularly their mammography and ultrasound tests.

‘I am doing the test! not every year, every 1-1.5 years!!! I am consistent with my tests!’(P 2 CY)

‘…we are doing our screening test every 6 months’ ‘we have it on our mind’ ‘It might be a genetic’ (P 3 CY)

“It's passed a lot of time from the last test, to tell the truth!” (P 6 CY)

‘Yes, we do our test, one year Pap test and mammography test, the next year ultrasound and self-examination.” (P 7 CY)

‘One year I do the mammogram the next year our ultrasound’ (P 8 CY)

“I did a mammography on my own from my early 40s (age). The fact that I am doing my mammography and ultrasound tests keep me feeling safe” (P 10 CY)

Beliefs

Do you believe that there is a risk for you to become ill from breast cancer?

Although Greek-Cypriot participants believed that there is a possibility to get breast cancer they feel that they are not particularly concerned with that possibility. They do not consider themselves to be in particular risk of being diagnosed with breast cancer, except in cases where there is a strong family history. Similarly, participants in Italy feel that they are not particularly at risk of being diagnosed with breast cancer. Consequently, the beliefs developed are consistent with the style of prevention they have adopted: everyone is aware that the screenings can be useful to prevent breast cancer, but there is a gap between the perception of the danger and the implementation of preventive practices.

'It can be terrible but not always, if taken in time you can also run for cover, if taken in time and follow certain preventive measures .... which I don't follow ...' (P1 IT)
'Medical checks are free so it would be foolish in my opinion not to go. In Emilia Romagna Region we are quite advantaged compared to other regions. Then there are many people who do not go to medical checks and will also have their reasons. I don't want to live with the heartache to have some disease. Definitely. I am 47 years old and I am very well that something will come to me sooner or later, ok? I can't live in terror, so I do the checks when I have to do them and, if I notice something in mine, in my health that is not normal, I ask clarification to the doctor.' (P2 IT)
'If I think or talk about diseases, I get anxious and I convince myself that I have all the diseases in the world, but I know it's just a fear. I don't know if is a risk for me to become ill from breast cancer, I do all the checks that the doctor tells me to do' (P3 IT)
'I don't know, but I think that prevention it's really important' (P4 IT)
'I don't want to think about disease' (P5 IT)

Portuguese participants **believe** that genetics is the main risk factor for breast cancer.

"Yes everyone .... Can I tell you why I am not doing this? Because I keep in mind that I may have something bad!!!.... I have nothing bad" (P 2 CY)
'My mother had cancer before many years ...we managed this. She is having her screening tests. But we never think that our dad will get breast cancer…we are doing our screening test every 6 months… we have it on our mind. 'It might be a genetic' (P 3 CY)

"Yes we are more anxious about that (cancer)!!! One more reason is my mom's breast cancer incident" (P 3 CY)

"The first type of cancer to women is breast cancer.....Very often…'It is genetic'.....you can get sick from any kind of disease' (P4 CY)

"I believe that cancer is hereditary!!! Which again I don't believe that i got sick from cancer" (P4 CY)

"Yes I believe that there is a risk because already get sick from thyroid cancer and my mother had cancer in uterus… I am afraid from other types of cancer' (P6 CY)

-"Yes I believe that there is a risk, due to the family history. But I know that it can be managed, we can managed it' …. 'It might be a genetic factor..'……. 'if you are lucky and find it early… if you do early diagnosis and after the proper therapy…'Yes I believe that there is a risk but I am ready to managed it" (P 8 CY)

"Yes I believe that there is a risk but I am not thinking of it too much… I worried more for other types of cancers… or other diseases' (P 9 CY)

'I believe it can happen! But I'm trying to get over that because we hear so much, so much type of cancer that get sick' (P 10 CY)

"It could be gene factors" (P1 POR)

"for example, as my parents also died, from the stomach and I have stomach problems" (P3 POR)

"I think there is a hereditary issue as well. When we are in a family, mothers, grandparents, who have already had breast cancer, we need to be even more vigilant" (P6 POR)

'This is going to be genetic because many of us have it". My mother died at the age of 54 with breast cancer' (P4 POR)

Do you believe that health habits such as smoking, nutrition have any impact on the occurrence of cancer?

Most of them agree that maintaining a healthy lifestyle helps to prevent the disease. Some others believed that other factors than the health habits like smoking, nutrition have an impact on the occurrence of illness/breast cancer, like stress/anxiety and environmental pollution (e.g. pollution/radiation). An interpretation of the participants' narratives conveys the message that they did not recognize (or poorly recognized) their personal responsibility to remain by adopting a healthy lifestyle (victimized themselves). Among the participants, there were also those who believe that there is no way to prevent the risk of getting breast cancer.

'We have it in our house…the Wi-Fi for example, the satellites…everything' (P 1 CY)

"I believe so, yes, smoking, and, diet, and, exercise!" (P 2 CY)

"Atmosphere in general! …Yes, this is where we live, the atmosphere in general!" (P2 CY)

'Sorrows, anxiety, are reasons that causes diseases." (P 4 CY)

“unhealthy eating, but from polluted products…..the anxiety as well…’ (P 5 CY)
“No, it doesn't matter at all” (P 7 CY)
“My mom always ate healthy food, she never smoked it, she always worked, and she got cancer. She never had an unhealthy lifestyle.” (P 8 CY)
“Yes, even though it can be difficult to follow a healthy nutrition regime and I don’t do physical exercises. I have many alibis: my engagement as caregiver.’ (P 1 IT)
‘In truth I lack the motivation to do anything, as I’m alone. I would like to have someone to walk with me, for example.’ (P 1 IT)
‘Yes. It is important to do physical exercises with others on. For example, if you walk with someone else, it’s possible to talk, to confront someone. It’ an important issue’(P2 IT)
Yes. I try to eat healthy and doing physical exercise, but it is difficult for me to do it regularly.’ (P5 IT)
“I think it has to do with both food and tobacco” (P2 POR)
“the type of life a person leads, food, sport, it is important” (P6 POR)
“Risk is always there. Even for a sportswoman, although she is healthy, she practices sports, there is always that risk” (P7 POR)
Manage anxiety (…) Even the food, today, is so altered (P2 POR)
It's more the stress (…) And the fat is also not good (P3 POR)
The risky routines like smoking, drinking, the food we have today (which we think it is a rich diet but which is so much added with junk food) (…) And the stress and anxiety (…) hence the importance of healthy lifestyles (P4 POR)

Attitudes

What is your attitude towards breast cancer?

Most of the participants are frightened about the issue of breast cancer, but this fear translates into different preventive modalities. For example, some **of the participants’** comments show an attitude of avoidance out of fear; **or driven by fear, some others** not perceiving themselves at risk or having an attitude towards simply carrying out the strictly necessary practices**.**

‘Prevention is very important…prevent the worst’ (P 2 CY)
“Okay I think that's pretty serious! Because okay after that thing.... If you don't understand … they are affected other organs ....” (P3 CY)
“The first type of cancer for women is breast cancer!”….. “Very common” (P 4 CY)
“We do not have in the close family cases of breast cancer but I lost a friend of mine at the age

of 43. Cancer can be detected in the skin, as inflammation, a rare type of cancer even. Doctors …cannot recognized this type of cancer. Usually you lose the patient. It was very scary... okay for the tumors are preventable. That's why I think it's difficult." (P 5 CY)

"Ok because I already had thyroid cancer, my mom has uterine cancer, we're worrying of other types of cancers than breast cancer!" (P 6 CY)

"I believe that you can manage cancer if you do early diagnosis…like my mother, she did a surgery and her therapy and she was fine" (P 7 CY)

"In our minds there is always the possibility that due to the history, we may suffer from it, but because I know it is manageable, I say if it happens, we will deal with it!" (P 7 CY)

"I think it is treatable if you diagnosed it in the early stages, as like my mum. She did the surgery, chemotherapy, radiation therapy, it was fine afterwards. She managed the breast cancer but the dementia that is now suffering now is a very difficult problem, I think is the worst disease" (P 8 CY)

"I believe the same if it happens, I believe I am ready to face it!" (P 8 CY)

"I can tell you that I am scared of other types of cancers more than breast cancer. I may be wrong about this…" (P 9 CY)

"If you are lucky to prevent breast cancer…to make an early diagnosis and a correct treatment." (P 10 CY)

"It's a terrible disease and it's scares me" (P 1 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" (P 2 IT)

"I am really scared about diseases in general" (P 3 IT)

"I am scared" (P 4 IT)

"I've never been worried about it or even wanted to think about I (…) If I have nothing, what am I thinking about? I already have so much to think about, not to think about one more (…) I don't prevent myself from anything" (P3 POR)

What is your attitude towards mammography screening?

In general, participants' attitudes toward preventing practices are linked with knowledge, beliefs and perceptions. Some participants avoid this practice, devaluing its benefits and trusting that their health is well. Of course, there is fears that arise from the lack of knowledge about the examination procedure. Participants who have **a family history of breast cancer they mention that they do their mammography on a systematic basis.**

'…is this safe to do every year mammography… I am afraid of radiology!' (P 4 CY)

"I am doing my mammography and ultrasound every 1-1, 5 year. 'Mammography helps to the

prevention of breast cancer'' (P 1 CY)

"To tell you the truth, I am doing mammography every 6 months and ultrasound. Breast Self-examination is okay when I feel that I am in more pain." (P 3 CY)

"I did my mammography five years ago!! In general, I am careless about myself!!! , I take care of others but ... I'm fed up with hospitals and doctors (P 4 CY)

I am 46, when I am 56 maybe I will do the test every year… 'Mammography helps to the prevention of breast cancer' (P 4 CY)

"Yes, I do my mammography every year …I usually go to my doctor and I do Mammography and ultrasound" (P 5 CY)

"Because I lost my sister in low, I am going every year to do mammography" (P 5 CY)

" I do not go to the national screening test because they do only mammography… usually I am going to my doctor for ultrasound and mammography" (P 5 CY)

"... the only thing that I am doing is mammography" (P 5 CY)

"We do our test, one year Pap test and mammography test, and the next year ultrasound and breast self-examination." (P 7 CY)

"One year I do the mammogram the next year our ultrasound!" (P 6 CY)

"I'm fine, I'm going to the gynecologist, every 1.5 years, okay, he's doing my examination …" (P 9 CY)

"Yes, this is a factor" (feels safe with ultrasound and mammography that's why avoid breast self-exam) (P 10 CY)

"I've never been worried about it or even wanted to think about it (…) If I have nothing, what am I thinking about? I already have so much to think about, not to think about one more (…) I don't prevent myself from anything" (P3 POR)

"I've done it all and I do it every two years. But I think this is natural. For me, it is natural. It's like going to the family doctor and you have to talk about your intimacy" (P6 POR)

'I am also very afraid of radiation' (P1 POR)

'I think it makes me sick to squeeze the breast (…) if the doctor asks I will do it. Only I complain a lot when I am taking the exam' (P3 POR)

'Radiation will damage other organs, causing osteoporosis, etc.' (P4 POR)

When we have someone in the family who has it, we are more awake to this situation (P4 POR)

'I do not go to screening appointments. Maybe I could overcome the fear if someone came with me" (P 1 IT)

'I am going to screening appointments when they called in' (P 2 IT)

"I always go when I receive the letter with the appointments" (P 3, 4, 5 IT)

Barriers

The barriers that emerged included: (a) lack of the time to think and perform Breast self-examination practices, (b) difficulties going to the hospital/health center due to the caregiving duties, (c) fears and feelings of guilt in dedicating time for oneself and not to the partner. Additional more generic barriers included: (a) lack of knowledge and skills, (b) fear of discovering anomalies/of getting sick, (c) discomfort and pain during the screening tests and (d) forgetting/failing to practice a routine of health prevention.

What do you perceive as barriers for doing a breast self-examination?

Lack of knowledge – lack of skills

"I do not understand if something is abnormal when I do BSE" (P 1 CY)

"In my case, it's the lack of knowledge" (P7 POR)

Lack of time due to their caregiver role

"I do not have enough time to have a shower and …I will do a BSE!' (P 2 CY)

Fear of the disease/discovering anomalies

"…maybe it scares me" (P10 CY)

"If I am thinking of this all the time…I think this would be a problem. It will cause me anxiety' (P 10 CY)

'It is not that people do not want to be tested, they are afraid. What we all feel is fear'(P4 POR)

'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 reasoning, I prefer don't know' (P 1 IT)

'It's a mental attitude; I want to forget about diseases' (P 5 IT)

Perceptions

"Can I tell you why I'm not doing this? Because I keep in mind that I may not have something!" (P2 CY) – (perception of not having something)

"I can't do BSE…but I think that because I am typical, I believe I will find it in the early stage" (P 5 CY) (perception of devaluing BSE)

"I used to do it. But, as that lady said, that the breast looked like everything that was lumps, as I call it, and I even went to the specialist and he said: "no, your chest is cloudy and how cloudy it has these ups and downs you find". So, I stopped doing it. (…)I, for me, it was all lumps [laughs]. And after all it wasn't any lumps, so it wasn't worth bothering me about. And so I don't even think about it anymore and I don't do it." (P3 POR)

"I find it difficult to stick to a routine even with medications, I can't do it" (P 2 IT)

"I didn't do it by myself because other things were on my mind, plus, I go to doctors' appointments. I don't do it by myself because I prefer dealing with it with doctors." (P 3 IT)
'I know that we should have adequate lifestyles and to do self-examination, but I don't be able. I cannot establish routines, to be regular in my lifestyle practices. I also have problems with taking medicines regularly.' (P 5 IT)
'I don't want to deal with disease. I want someone to think about it for me and tell me what to do'(P 5 IT)

Discomfort and pain
"BSE It is uncomfortable, no doubt. Mammography is a bit painful procedure " (P1 POR)
"It's uncomfortable; I don't really like doing it" (P2 POR)

Ignorance, prejudice with the body
"I think that the ignorance of the situation contributes but there are also prejudices in relation to the body, many times. Today we think it doesn't exist. But I think it still exists. And therefore, it is also this prejudice that sometimes prevents people from having these tests" (P6 POR)

(Looking back) have you missed (or avoided) any screening appointments?

As for carrying out medical screenings, there are those who claim to comply with their attendance, but there are also those who assume that they have already forgotten about appointments because they were concerned about other problems.

"For sure I left some appointments behind. For example, now I wanted to visit an ophthalmologist but I left it" (P 2 CY)
"Yes, I left…because my mother had an appointments to the hospital" (P 6 CY)
'Yes, many times' (P 1 IT)
'No, always takes advantage of the screening programs'(P3 IT)
"I always went to doctor's appointments for checkups" (P4 IT)
'I passively follow what doctors tell me to do. I'm very happy when I receive the invitations for checkups (mammography, cervical screening). I always went to doctor's appointments for checkups'(P5 IT)
"Yes, I already missed it" (P1 POR)
"Look, because I don't have time, for me. It seems that with two completely dependent children, me working, I do not have a minute to spare. I lack minutes, sometimes, to sleep." (P2 POR)
"I already missed it (…) I take a lot of medication and I have trouble remembering things and sometimes I forget. The last time I didn't take the exam was because of forgetfulness. (…), it

was my health, my mother-in-law, then it was my sister, it was all followed. My sister-in-law, who I helped a lot in the bath, with food, was a constant struggle (...) I only went 2 or 3 times. It wasn't that I didn't want to go, but a lot was happening to me (P5 POR)

Benefits

Do you know the benefits of early recognition of breast cancer?

Most of the participants stress its importance of early detection of breast cancer for the treatment and only one appeared to be unaware of the **benefits**.

"On prevention" (P1, 2, 4 CY)
"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)
"Prevention to make it easier to treat. Doing early diagnosis ...like my mother, she did a surgery and her therapy and she is fine" (P 8 CY)
"It will be easier to manage cancer if you find it at the earlier stage" (P 9 CY)
"If you are lucky and find it early… if you do early diagnosis and after the proper therapy…" (P 10 CY)
"If you are diagnosed early on, if you do some sort of prevention, you can fight breast cancer" (P 1 IT)
'Yes' (P2, 3, 4, 5 IT)
"I'm not really into it" (P3 POR)
'I also think that if it is detected early, it may be easier, it can be removed and, sometimes, without the need for treatments" (P2 POR)
'The earlier the diagnosis, the better. I think people today are also more awake to this and in fact WHO has been warning. There is no one who is not afraid of this disease or who has not heard of it' (P4 POR)

SECTION 2: PERSONAL INVOLVEMENT

Do you feel that your caregiver role has somehow influenced your life?

All participants agreed that their caregiver role changed their life on many different levels (i.e. psychological, emotional and social and physical level). They described feeling guilty, anger, nervous, loneliness, depression, anxiety, tiredness and exhaustion and fear of losing the person

they care for. This experience makes them to find some positive aspects for their life, like changing priorities and satisfaction offering care to the other person.

"When you are door closed you are alone! Of course, change my life 180°. I see life differently now… I prefer to be at home alone. Rarely I go out' (P 1 CY)
'I feel guilty when I go out and I feel terribly bad psychologically when I go out…'
'I usually get rest only after my husband slept' (P 1 CY)
'I get angry very often and fighting with him" (P 1 CY)
"I will tell you…I was an independent person…now I can't go anywhere. I want to sit only and just watching the wall' (P 2 CY)
'I only go out for the dog… I don't want to do exercise anymore' (P 2 CY)
'Sometimes I am nervous so I go to the bedroom to relax…" (P 2 CY)
My life change…very quick rhythm' 'priority is my father' (P 3 CY)
"I used to live with fear, I always worrying! I was bad psychologically, many times... a lot of grief let's say. I feel that I learned many things from this situation. I always take care my mother, not because I have to but because I want to care for her. This is my satisfaction'. (P 4 CY)
"Yes, it affected me a lot! I became diabetic. …I am exhausted. I do not trust anyone else… I have a sister but okay; my sister is participated only when serious decisions need to be take" (P 5 CY)
"I get angry but never express my feelings!" (P 5 CY)
I feel now to have more patience and satisfaction due to the care I offer to her' (P 5 CY)
"I do not take care myself... the only thing that I am doing is mammography" (P 5 CY)
"This fact was stressful…we tried to get used to the change of his general situation (side effect of chemotherapy)' (P 7 CY)
'Yes' (P 1, 2, 5 IT)
'Yes, definitely' (P 4 IT)
'My life changed 90%. It was turned upside down. I was a bitch who likes to go out like me. Now I'm always at home' (P3 POR)
'Basically, it leads to some restrictions, some options and directions in our life conditioned by caring' (P5 POR)
"At all levels. At a professional level, at the level of ... I am a widow but I have a partner, right? At the marital level. At all levels. On a social level, I don't have time for friends" (P1 POR)
"I always have to have someone at home because my son is a person he doesn't eat, if he doesn't have to eat he doesn't eat, if I don't give him water, he doesn't drink, if he has a dirty nose I have to go there and clean his nose, "Mom takes the monkey out of my nose", scratching

her head. I have to do everything, everything, and everything because he is a quadriplegic, he does not move anything. I have to change his diaper, remove the poo, pour the pee, because he has ... He does it for the bag, I have to dump the bag, every three days I have to change the bag" (P4 POR)

'Now with my husband's concern I can no longer leave [the medication] (...) also because of the need to take care of him during the day. And not being able to have meals at the right time there, that happened often. That I wasn't even hungry, notion. Passed me. I forgot. He was first. I had appointments, exams, etc.' (P1 POR)

'...do not take medication but according to the concerns of the day, taking care of my daughter, I have difficulty not falling asleep but after a 2-3 hour sleep I wake up and can no longer fall asleep'(P2 POR)

"It radically changed my way of being in life. Because that's the way it is, we are a couple who share a life, who make plans for the future and, suddenly, the whole thing turns around and we become informal carers for the husband, as it is my case. I do not know if that is the case with that lady. Therefore, our life has completely changed. Now that does not stop me from being happy. Taking care of my husband and being happy. And to have my own life" (P6 POR)

'I don't do any exercise now, I walked but I gave up (...) for lack of motivation' (P1 POR)

'I was at the gym for 2 years and I had to stop' (P2 POR)

'I was going swimming with my sister but since January I haven't been' (P3 POR)

'I used to do water aerobics but I stopped doing it after my daughter got worse and I'm also worse. Now I am really tired' (P4 POR)

"In my case, while I didn't understand what kind of problem my husband was having, what illness it was, he was someone else and I didn't understand. Those two years that I did not realize what the disease was, nor did anyone tell me, nor did anyone diagnose it, and he was always being followed by a psychiatrist, it was the two most difficult years of my life and then yes. I felt lost, I felt dejected, although I am a very positive person, because I am and turn around easily. I always try the best in life. I think life has so much good that we cannot cling to disgrace. But those two years, my husband was someone else and that affected me a lot." (P6 POR)

After my daughter, got sick I was extremely tired (P4 POR)

Even my daughter says: "it seems that the mother has a very low self-esteem and must have some problem" in her head "due to the fact that she does not sleep (P5 POR)

Has your caregiver role influenced your screening practices in any way? (Positively or negatively?)

Some participants share the feeling of responsibility to the person they care for and their family as one of the reasons to do their screening tests regularly. Some others due to their role, they given up their personal care to dedicate themselves to the other person and they missed some appointments or they postpone it.

Feeling more responsible

"Yes, I do my exams! When I feel something on me, I run to the doctor … let's just say I have to be strong if I have something wrong with me who's is going to take care my husband?" (P1 CY)
"I take care myself. I am doing my tests; I go to the doctor.... If I feel any difference" (P 3 CY)
'Positively, I need to take care of myself in order to take care of others too' (P 4 IT)
"I don't miss it because that's how I say it; I have my husband at home who helps, right? For me to come here, my husband had to stay there" (P4 POR)

Postpone appointments

".... I left appointments behind. For example, now I wanted to visit an ophthalmologist but I left it behind "P 2 CY
"Although I have osteoporosis, I don't want to do exercise I want only to sit I feel tired" (P 2 CY)
"Taking care of a person is very stressful and difficult situation. Is difficult to go to your appointments (mammography) or to go to the doctor when you are sick, even though to go to work. … I cancelled an appointment before I had help from a paid carer" (P 6 CY)
'I missed an appointment with the neuropsychologist, at the moment I'm being seen. I had almost asked to make the appointment together with my daughter, she gave me the list with appointments for three months but in the meantime, she changed it and I changed the dates, and I still have not had time to go and reschedule with the Doctor' (P4 POR)

Dependence on other people

"I don't because it is like that, I had my husband at home five, six years. And he was walking, where I was, he was. Therefore, our family doctor is the same. Making an appointment for one was the other. And whenever I needed to go alone, I always asked for a family member or friend, luckily, friends are amazing and help us a lot. And therefore, when I needed it, there are

friends who temporarily replace me, or family, or neighbors because the neighbors are also our first family, who sometimes lend a hand and care about us" (P6 POR)

SECTION 3: SIGNIFICANT OTHERS EXPERIENCES

Are experiences described by your relatives in some way affecting you?

The informal carer role (depends on the time being involved/burden) affects the way they act in taking care oneself – some of them act as a motivator factor to take care their self to do their screening tests (because they are responsible for the person they care for and their family) and some other neglect their self and their health. In a more positive point of view, one Portuguese participant considers that being a caregiver has developed the competence of tolerance, patience and kindness towards others.

'Yes, very stressful situation, for example you see the person from the beginning of his/her illness, the complications from chemotherapy, to take care the gastrostomy…' (P 7 CY)
"After my mother's surgery the doctor inform us that we should do every year our screening test for breast cancer' (P 7 CY)
"both of us (3 sisters) we arranged our appointments together. Each other we motive each other' (P 7 CY)
"Yes, a lot of my relatives got cancer. This made me go to screening appointments regularly." (P 2 IT)
"Yes, my grandparents and my father got cancer, so I regularly do checkups." (P 3 IT)
"I took care of a friend who had cancer; it made me more afraid of diseases." (P 4 IT)
"Maybe, more kindness to other people because we are taking care of the person, we are also more emotional ... No, how is it? It has more emotions towards other people. We talk to other people like when we talk to who we are caring for (...) and we already have a second view of things. That we are talking to a person, for example, if the person is upset or something, we realize that it may be for another ... She is upset, but it is not with you, it is with another person, but she cannot separate things well, so we help so much. This is my case." (P7 POR)

SECTION 4: MOTIVATION FACTORS

What are the factors that drive you to engage in breast self-examination?

Possible factors that encourage participants in BSE are past illness experience (family member or a person they know), the fear of the disease, a health professional (their doctors) a friend or

a family member (sister), advanced age and campaign from nonprofit organizations, in TV and newspapers.

Past illness experience

"If I heard that a person I know has cancer…or died from cancer motivate me to do my screening tests" (P 5 CY)

Significant other

"After my mother's surgery the doctor inform us that we should do every year our screening test for breast cancer" (P 8 CY)

"Both of us (3 sisters) we arranged our appointments together…we motivate each other" (P 8 CY)

"Usually I do my test with a friend of mine: (P 9 CY)

Campaigns

*"Advertisements, Europa Donna" (*P 8 CY)

Health care professionals

"A Gynecologist motivate me to do my test, after my aunt died from breast cancer' P 10 CY

Responsibility to care for their family

"I need to take care of myself, otherwise who is going to take care of my family?" (P 4 IT)

Fear of the disease

"*Risk awareness*" *(P1 POR)*

"*It is the fear of risk. Minimize risk*" *(P5 POR)*

"*I think it's essentially fear" (P7 POR)*

"*I am to avoid and detect early if something comes up, since I have already removed a lump from the breast and I must always be alert*" *(P2 POR)*

"*When, the first time, calcifications were detected, I was so scared. But it was normal for me to go to the doctor and get tested. There, it started there. From there, it is a routine; it is a normal thing, for me, to watch, to go to the doctor. And my motivation ... Of course, I am afraid, it is evident, but I even know that I am not a high-risk person, because I have no one with cancer in the family by my side, nor am I a high-risk person*" *(P6 POR)*

I used to do palpation but now I do it more often, after I had a problem and the age is already advancing (P6 POR)

SECTION 5: TECHNOLOGY PREFERENCES

What do you thing will be useful to suggest to us to have in mind when we design an app focus on breast cancer prevention?

In this field, most of the participants mention to be familiar with mobile applications and usually used it to relax, but they also mention that they are not familiar with applications aimed at preventing disease. According to the participants, some elements should be present in an application for the prevention of breast cancer:

- Video with guidelines
- Supporting forum groups (with health professionals and informal carers)
- Reminders for their appointments
- Chat with self-mutual help groups for informal carers to share prevention path together with other informal carers for example going together to medical appointments in order to deal with the fear related to them or giving advice on including preventive practices back into their daily lives.
- Simple and direct clinical help: humanization of the medical-health service, therefore support from operators that is easy and immediate to understand and does not use excessively technical terminology. It could also include the opportunity to contact specialists for doubts or questions related to one's health.
- Focus on global health: including elements also on the nutritional side (eg diets / healthy recipes that give insights on the preparation of meals) fitness tips, such as short daily workouts, meditation / mindfulness exercises.
- Stories of people who tell their experience with the disease and how they managed their health, from a physical and psychological point of view.
- Meetings with experts on this topic

"Video with guidelines of BSE" (P1, 2, 5, 6 CY)

"Talking to people who have gone through the same thing ...in order to know that you are not alone" (P2 CY)

"Groups for support I would be interested!" (P3 CY)

"We are looking information, Yes!" (P3 CY)

"I am using forums with health professionals of PASYKAF" (P3, 9 CY)

"Information about some diseases …. texts with information only…I use the computer to find information from scientific articles for example for dementia disease and seminars as well" (P 5 CY)

"I am interested with an app Need for Educational Seminars" (P 5 CY)

"A reminder, for example, Dr …. send us a reminder message for our screening test for breast cancer" (P 7, 8, 4 CY)

"A group seminar would be very interesting" (P 7 CY)

'Only For information' (P 10 CY)

"Information about symptoms; a reminder to do self-breast examinations or mammography screening" (P 1 IT)

"Sharing content with other users, connecting with them, not only keeping track of self-breast examination" "An app with more general content could be useful, only breast cancer is reductive" (P 2 IT)

"A simple language, with terms easy to understand and not too much clinical" (P 4 IT)

"An app that helps to create healthy habits in general, like nutrition, or work out" "I believe the issue is more holistic, because most informal carers are woman and there are a lot of issues that come into the picture" (P 5 IT)

"I think that also making the application very tiring, for those who don't have time ... It has to be very simple and go directly to the subject, like: be comprehensive, there are those who know how to do the palpation, there are others who do not. It could also be one that exemplifies how we do palpation or breast self-examination. Another would be the reminder, to be already directed or interconnected with the IPO, right. Or when are we going to do the exams and then have a reminder on the phone like this, look: "this month there is an exam". So, giving these indications, which we receive by mail, but sometimes, we arrange the letters, which has already happened to me, oh man, and then with everyday life, we don't ... then we still have more work because we have to go to the headquarters right there and then they have to book." (P2 POR)

"It should be intuitive because I don't like complicated things, with reminders and if there is any interaction of didactic games, I think it becomes attractive to move and work a little with it (...) And information, of course, that has to be associated (...) The more intervention by professionals and also with some interventions of real cases of people to report their experiences. I think this is also important for the person to deal with it (...) A forum or some testimonials from people have gone through this situation" (P5 POR)

"I think that this final interaction would be important even for... There are people who have cancer and need to let off steam and who, perhaps, was easier to talk to another person who has had it. What I think is that the application should have an information and game dynamic, really. But also, to say: "do your screening or your surveillance in this way". Teaching, isn't it? Teach either by play or by image. A dynamic that we can click on and say: "Do I do it well? Am I like this?" It's an experience, I can't do it with someone else, I make a doll there, for example. I think it would be funny. Then give that information and remember that from time to time, it would be important for us to do either our self-assessment or self… (….) " (P6 POR)

'It would have to be something very easily accessible. Which I think is useful (...) it could help to rest, and relax, the person knows that he has those reminders (...) My daughter, for example, is sick but has everything written down on her phone. The appointments, the exams, the date of the operation and she knows everything without getting tired. She has the area of health, the area of friends, birthdays, food, she uses it for everything' (P4 POR)

Are you familiar with Applications related to illness prevention?

Most of the participants justify being familiar and some other not being familiar with mobile applications due to lack of knowledge and time.

"I can say that I am familiar with apps! I have a smart phone" (P4 CY)
"I relax with the mobile" (P5 CY)
"I am interested with an app" (P5 CY)
'Yes' (P1, 2, 3, 4, 5 IT)
"So, I don't know how to do anything else on the phone. It's just calls. (...) I don't understand these things very well" (P3 POR)
"I know it exists but for now I don't have time to explore these applications" (P5 POR)
"I don't have that habit of fetching apps, I'm frank. Especially because I'm not a computer expert and then it gets stuck and then it's a problem" (P6 POR)
'There are people who sometimes are of the opinion the less they know the better' (P2 POR)
'I just for calls' (P1 POR)
I use it to search for information, news, email, rarely games, but other than calls, information and email. (P2 POR)
I really like to look at Facebook (...) for alarm clock yes. For queries not, I put everything on the refrigerator door (P3 POR)
Yes, I sometimes use it for social networks, email, and some research (P6 POR)

PROFESSIONALS FOCUS GROUP RESULTS

Pre- section: Knowledge of the informal carer' s role (from professional point of view)

Are you in a direct contact with informal carers at your work?

The majority of the experts in the Greek-Cypriot and Italian focus groups were professionals in the clinical field. Their clinical experience included working with people diagnosed with and living with breast cancer (i.e. a doctor, an advance nurse, a breast cancer nurse, a psychologist and ergo therapist, psychotherapy, nutritionist). Two of the participants have an academic training and expertise in topics directly related to patients diagnosed with breast cancer and their informal carers. One of the participants specializes in the field of nursing and the other one is specialized in health promotion. The Portuguese professionals that were interviewed hold an academic training in the field of psychology or social assistance. Their clinical experience includes cancer institutions where they treat cancer patients and their families.

'My experience is during the clinical practice of nurse's students in the community field… we come in contact with (are indirect contact with) informal carers at the patient's home' (P1 CY)
'… We take care persons diagnosed with breast cancer and we come in contact with their family members who accompany and support that person' (P1 CY)
'Daily I interact with families of persons with a breast cancer experience' (P4 CY)
'Throughout our practice, we are in direct contact with informal carers' (P1,2,3,4 IT)
'Yes in direct contact with informal carers across the disease trajectory' (P2,3,4,5 POR)

Could the informal carer's role influence their habits for breast cancer prevention?

During the focus groups, the opinions and knowledge of the professionals have coherently described a unique reality. This reality is reflected and agrees to the narration of the informal carers' focus groups.

Generally, the informal carers in relation to the prevention of breast cancer adopted two macro categories of behaviors as these were described. In both categories, it appears that the experience of caring for a loved one diagnosed with breast cancer is a powerful influential event in the informal carers 's life. Despite the similarity of the experience, it appears that it can be manifested both in a negative and in a positive way:

- One is characterized by informal carers who, due to their commitment to care, do not adhere to preventive practices and exams:
    - lack of time due to many responsibilities and
    - fear of the cancer disease (e.g. fear of being diagnosed with cancer)

- The other category, is characterized by informal carers who, because of their care experience, are meticulous in following the prevention practices:
    - responsibility towards the person they care for and own family
    - the high risk to get cancer

*Informal carers are usually **looking for psychological support for oneself,** 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)*

*'Informal carers 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)

*'Yes. There are those who become more attentive and those who let themselves go, because **they focus more on the patient**" (P1 IT)*

'Yes. In the final stages of the illness [of the patient] the exams are more often postponed or skipped by the informal carers"(P2 IT)

*Yes. "**Some informal carers develop fears** and **a total phobia** for any type of prevention in relation to the disease' (P3 IT)*

*'However, **other informal carers are always attentive, meticulous** and have an open attitude to any proposal" (P3 IT)*

*"**Women do not go because they are informal carers** 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 carers can't even leave them alone" (P3 POR)*

*"(...) where am I going **to find time** and **who will stay with the patient**?" (P4 POR)*

"But the question is: how does the informal carers, being a caregiver, ending up being very conditioned in terms of time, manage to have availability for?" (P6 POR)

Sections 1: Mapping the needs, attitudes, knowledge, believes and perceptions of informal carers – Professionals knowledge

What do you think are the educational priorities that should be set in a breast cancer education program?

Professionals stipulate as their educational priorities the dissemination of reliable information about preventive behaviors, such as breast self-examination, which is an examination that still unknown how to perform or devalued by some women (POR). Other professionals consider that, emphasis should also be placed on the (engaging) way that the education program is

delivered additionally to the content. Furthermore, they proposed that, the educational program must include topics from all levels of prevention: primary, secondary, and tertiary as well (CY). According to professionals, the **educational part** of the project should focus mainly on the **motivational, emotional side and to offer reliable information on primary prevention, about breast cancer (e.g. treatment) and lifestyle changes (e.g. physical exercise, healthy diet, losing weight)**.

Specifically:

- The informal carer must be motivated to engage in prevention by adhering to practices in a positive sense:
    - Reminding her that only **if she is healthy**, both physically and psychologically, she will be able to take care of her loved one.
    - Important to teach them **to manage their time**, also giving priority to themselves, as this will make them feel better about themselves and others.In conjunction with this, adherence to preventive practices will allow them to manage their health and being able to continue to be a caregiver.

- The second priority must be **on the emotional side**. It is necessary to teach them to accept, embrace and manage their emotions (e.g. emphasis on the negative ones). We need to be educating them to express their feeling (good and bad) and not to feel guilty, or emotions such as fear, anger, sadness and helplessness. If properly managed, these sensations can make the person grow positively and also improve the caregiving role that they have undertaken.

'The first thing that comes in my mind is not the content of the training but ***the way the informal carer's will be trained****. It must be* ***simple, concise, and understandable, without causing further psychological burden to them****. For me the content of the education program is secondary. In the second stage, the training program could include both primary, secondary and tertiary prevention' (P1 CY)*

'I believe that we should send a message that ***prevention saves lives*** *and convince the informal carers that* ***prevention saves lives****. Also that it is something that all women need to do for their own health. So to convince them with this message that by doing their screening test and BSE regularly... the results will be what we want them to be. And not to detect breast cancer late and move to secondary and tertiary prevention such as CT Scan etc'(P2 CY)*

'...okay almost all of us known about the method of mammography but we do not know that ***lifestyle changes can be a factor that can prevent cancer.*** *The way that this approach to living can have a positive impact, is an area that reveals significant lack of knowledge. So we focus on that firstly...but it is good to point out the mammography, the Breast self-examination...plus the genetic testing and certainly a check should be done to see if there is a predisposition. Apart from the genetic predisposition, there is also what they know about to change their lifestyle.*

And the exact meaning of changing their way of life, I think they should be very well informed' (P3 CY)

'… many times informal carers ***do not know the right way to support*** *(psychologically and physically) the person who is suffering (often in silence) in their environment. They often turn to us to inform them for the right ways to support their own person' (P2 CY)*

'I believe that technology has entered our lives for good. So we have to take advantage of the available ***technology****. Both the patient and the informal carers* ***should take advantage of this experience and help them to adopt preventive practices'*** *(P4CY)*

'The educational program should be ***short and understandable for everyone****. Also, for informal carers but also for people who are sick. The* ***program should include and the three the elements of prevention****. But* ***after the person diagnosed*** *with breast cancer... plays an important role. The continuity is very important. For example, being diagnosed with breast cancer does not mean that prevention it is stopped because the person is diagnosed'(P5 CY)*

"Giving priority to the ***motivational side****, an informal carer can only play his role if she is healthy" (P1 IT)*

"A ***basic knowledge*** *on the theme is more or less owned by everyone" (P2 IT)*

"Priority on ***the emotional side****. Teach to accept and manage emotions. An education to feel, not to feel guilty of emotions such as fear, anger, sadness. Accept the limit of what you can do, manage the feeling of helplessness' (P3 IT)*

"Give ***tools to*** *better* ***manage real problems*** *rather than notions, as we are submerged by them" (P3 IT)*

"Teaching ***how to manage time****, as the lack of time is a justification. Teaching to give priority also to herself, to her own well-being "(P4 IT)*

"I think it would be important to address ***the way that women can make the correct palpation, as primary prevention,*** *yes? Shall we talk like this? Correct palpation because many women do not know how, sometimes grope more and get trampled" (P4 POR)*

'… giving information to the informal carer that ***physical exercise is necessary*** *for him/her to be able to take care, because if he/she is not feeling well either physically or emotionally, he/she is also unable to take care of the other. (…)"today you must walk a kilometer", so that if the person also has to relax a little, but goals like this, imagine, nothing too excessive or that takes up too much time, that people look and realize that they can do that little bit'(P5 POR)*

*'****More emotional care****. The prospect that strategies can be positive for regulating stress, right? In order, for example, to have someone with whom to talk, to have a moment for yourself, to have a set of social activities, to have here a set of indications, not only in the perspective of the prevention of breast cancer, but to promote well-being of the person…'(P2 POR)*

What should be included in a breast cancer educational program in order to motivate informal carers to adopt breast cancer prevention behaviors?

Firstly, professionals believed that a breast cancer educational program should include themes in order **to convince informal carers that prevention saves lives and to motivate them to do their screening tests and BSE regularly.** It is necessary to make carers understand that only by taking care of themselves they will be able to adequately care for their loved ones. It is important for their mental and physical health, for their well-being, to dedicate time for themselves, adopting a healthy and consistent lifestyle. A practice advocated by professionals, in favor of health and well-being, is changing lifestyle (physical exercise, healthy diet, losing weight) ***and this can be one factor that can prevent cancer.*** In order to manage **the fear of cancer disease** this program should offer to informal cares reliable information on primary prevention of breast cancer and information on breast cancer disease and its treatment. In conjunction with this, adherence to preventive practices will allow them to manage their health and being able to continue to be a caregiver.

A breast cancer education program may include some activities suggestions and exemplification, at a non-advanced but accessible level. This segment should demonstrate how the practice of physical activity is also important for mental health, since it contributes to regulating the stress levels, characteristics of informal carers, and to having a moment for themselves. Different motivational factors are listed for adherence to preventive behaviors against breast cancer: positive survival rates, sharing testimonies of those who were early-detected cancer and were able to recover effectively or simply women who, by regularly do the screening; can be calm because they know they are healthy. Another important motivator factor to be included in the breast cancer educational program is the **use of technology** to promote preventative behaviors.

*'I believe that we should send a message that **prevention saves lives** and demonstrate the ways that **prevention can save lives**. Also, that it is something that all women need to do for their own health. So, to convince them with this message that by doing their screening test and BSE regularly... the results will be what we want them to be. And not to detect breast cancer late and move to secondary and tertiary prevention such as CT Scan etc'(P2 CY)*

'The main subjects that a training program should include are the various forms of prevention' (P5CY)

*'I think that over time and with the various **wellness campaigns** that have been done we see that people are more aware, they came closer to the experience of breast cancer, so my opinion is that we have really seen a significant improvement in the general population in recent years' (P2 CY)*

*'Technology has now entered our lives for good, so more people are involved and **using technology in their lives**, so I think it's very important to **use technology to promote preventative behaviors**' (P2 CY)*

*'I believe it is **ignorance.** That is, when we talk about primary prevention, we are definitely talking about **lifestyle changes**. Losing weight. Not many people know that being overweight can cause cancer... so I think with simple instructions for the importance of the exercise. They do not know that all these things are predispose factors for cancer disease. So I think it is the fear for this disease since we have all experienced this but I think it is most the ignorance, **the lack of knowledge**. They don't know how to do it. They do not know how to follow these simple instructions, which would be good through the application to be seen or taught through an educational program. To give clear instructions such as that obesity and lack of exercise are predispose factors for breast cancer. All to be scientifically updated' (P3 CY)*

*'I believe that **technology has entered our lives for good**...so we have to take advantage of the available technology. Both the patient and the informal carer should take advantage of this lived experience (i.e. being diagnosed with breast cancer and providing caregiving) and adopt a precautionary measure. So I think it's very important that this application is done and I think it's very good' (P4CY)*

*'I should also add that… we can **manage the fear of cancer disease** when we add aspects to the program and the application. To **give information about the disease and the treatment.** When someone gets sick is important to **encourage them that there are new treatments, innovative treatments with fewer side effects, with much better results.** So these can be added to encourage, empowered and motivate the patient with the right information so that they are properly informed and everyone did the right prevention (secondary/tertiary)' (P4 CY)*

*"We need to make it clear that if they take time for them, **if they take care of their well-being and health, their loved ones will also feel better.** We take better care of others if we are healthy"(P3 IT)*

*"Knowing that they have a certain predisposition to the disease (as their parents are suffering from it), my patients are **motivated to implement healthy lifestyles**." **Physical activity, nutrition, psychological well-being** are activities on which the individual feels he can make a difference' (P4 IT)*

*'But **giving information** to the informal carer that... **Physical exercise** is necessary for him/her to be able to take care, because if he/she is not feeling well either physically or emotionally, he/she is also unable to take care of the other. (…)"today you must walk a kilometer", so that if the person also has to relax a little, but goals like this, imagine, nothing too excessive or that takes up too much time, that people look and realize that they can do that little bit" (P5 POR)*

*"…the importance of **exercising indoors** but leaving the house will be better" (P4 POR)*

*"More **emotional care**. The prospect that strategies can be **positive for regulating stress**, right? In order, for example, to have someone with whom to talk, to have a moment for yourself, to have a set of social activities, to have here a set of indications, not only in the perspective of the prevention of breast cancer, but to promote well-being of the person and, in this case, of the informal carer" (P2 POR)*

*"something else that would be **funny** to have in the application, **relaxation exercises**, **breathing** that help to calm down, which is also a simple thing to do and also promotes well-being" (P3 POR)*

*'I think it would be relevant to have **a survival rate and how**, for example, a late diagnosis affects the patient's quality of life' (P6 POR)*

*'...**sharing testimonies from volunteers** of Liga, so, just a short time ago, a lady shared with me that this is how she detected it. Participates in the screening and in that two-year interval, if it weren't for palpation, it would probably be too late (...) Testimonies of people who, for example, through screening, have detected early ... So, here is to report that it was actually, due to screening, the participation of screening that allowed to detect, early, so, a malignant tumor and, therefore, happily things end up having a course' (P6 POR)*

*'I think it will make more sense, like: if you don't do breast screening what, what are the risks you run? I think that more in this sense of **educating,** rather than... Imagine... What can happen if it is detected three months in advance?' (P3 POR)*

Extra themes

Challenging the preventive role of screening

"Some people think it's more useful to engage in nutrition, physical activity rather than screening. In this way they perceive that they are doing something for themselves, while the screening doesn't appear to them as a true prevention, as they are only looking for the disease" (P2 IT)

Barriers

What factors do you believe that may be perceived as barriers to Breast Self-Examination in relation to the role of informal carer?

The issue of psychological barriers is therefore closely linked to the **fear** that informal carers can have in undergoing examinations. All the professionals have unanimously identified as the

main fear the one of **getting ill and suffering**. On the one hand, getting ill **would no longer allow them to take care of their loved one**. On the other hand, the fear of suffering is not only related to the disease, but also to the treatment themselves (which in oncology can be notoriously painful and burdensome). So, a second identified fear is **linked to oncology**, regardless of one's role as a caregiver, as it awakens the fear of dying. Many women delude themselves that until they do not perform a medical examination, they will not be sick; they prefer not knowing the outcome of the exam to consider themselves healthy. To this, informal cares add a **sense of responsibility for caring** for their loved one, which therefore takes them further away from prevention. Lack of knowledge (lifestyle changes/they do not know how to do BSE) is another barrier that is link with BSE test and lack of time… taboo/shame

'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)*

'...many times ***the avoidance of dealing with*** *or approaching a difficult problem may be* ***a defense mechanism in an additional traumatic event.*** *They experience a traumatic event...the diagnosis of their own person so it may be a subconscious defense mechanism to avoid'(P2 CY)*

'I believe ***it is ignorance that is mainly generated by prejudice.*** *That is, when we talk about primary prevention we are definitely talking about lifestyle changes. Losing weight. Not many people know that being overweight can cause cancer... so I think with simple instructions for the importance of the exercise. They do not know that all these things are predispose factors for cancer disease. So I think it is* ***the fear for this disease*** *since we have all experienced this but I think it is most the ignorance,* ***the lack of knowledge****. They don't know how to do it. They do not know how to follow these simple instructions, which would be good through the application to be seen or taught through an educational program. To give clear instructions such as that obesity and lack of exercise are predispose factors for breast cancer. All to be scientifically updated' (P3 CY)*

*'****Fear is the first thing for me****. The main reason is that they have experienced…an experience that is not the most pleasant either for a cancer patient or for the informal carer. Unfortunately,* ***the side effects of the treatment*** *is another disadvantage. It makes things more difficult and tragic. A picture that I see every day in my work is an image that comes to the mind of every informal carer, the side effects of nausea, vomiting, weight loss. All this creates a bad image, so the informal carer is afraid to go and do the obvious, which is prevention. Even today, there are people who cannot say the word cancer. It is a taboo* ***topic****' (P4 CY)*

*‘**They afraid** to find something wrong during the examination’ (P5 CY)*

*‘Is the wrong way. I mean **they do not know how to do BSE** in the right way. I mean they do not know exactly how to do it’ (P5 CY)*

*"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)*

*"A **psychological difficulty** rather than a difficulty in accessing services"(P1 IT)*

*"Provinces have lesser adherence [to the prevention exams] than cities. I think sometimes it's a **cultural** and **mentality** issue. Some women think: if I hadn't done the exam, I wouldn't have gotten sick." (P2 IT)*

*"It's true. In the countryside and in the mountains, **going to the doctor is something exceptional**, which is done when you feel terrible. Going to the hospital is an almost disused practice. "(P3 IT)*

*"Many carers talk to me about their **solitude**, this is a blocking element of great suffering." (P3 IT)*

*"I receive people who, going to a **nutritionist** for themselves or for their relatives, start from the premise of taking care. They have already overcome the barriers. "(P4 IT)*

*‘…precisely because she does not find the lump, so "I don't need to do the mammogram, I don't need to go to the doctor because **I feel and I do not see anything**"(P2 POR)*

*‘**Denying,** often, that the problem does not want to accept’ (P3 POR)*

*‘They are very **aware** of this issue, **through advertising**, through television. They are really sensitized and adhere. Now, I think that, really, they cannot for time, **lack of time,** or so, but they are very sensitized and want to do the treatments’ (P4 POR)*

*‘**Lack of knowledge**, because **they don't know how to do it**. And because they are not aware of the importance of. I think it's a lot of **ignorance,** because they have no perception of how it works’ (P6 POR)*

*‘They **devalue**, they think that it only happens to others, the truth is this, is that this is still lived a lot, "it only happens to others"(P6 POR)*

What are the potential fears for adopting breast cancer prevention behavior in practice?

*‘In today's world where everything is moving very fast, the modern woman **does not have time to become ill.** It may seem strange, but the obligations are so many that we forget ourselves. We **forget to take care of ourselves**. Although our health is so important because we do so many things, **we often neglect our health and ourselves**. Maybe this is a very important part that we have to do… our mammogram, a routine examination with our doctor and I say okay I go next month I go next month and from month to month we continue’ (P2 CY)*

‘It has happened to me many times that I hear from patients or informal carers that I had a lot of things on my mind or ***I didn't have time*** *or a lot of things happened to me, maybe important events in life that delayed me from my screening tests’ (P2 CY)*

"The ***fear of getting sick****. They think: if I go to the visit I can discover that I am sick, as long as I don’t go I remain healthy"(P1 IT)*

"Many ***anxieties and fears*** *revolve* ***around oncology****. There is the idea of entering a world in which you will feel ill and die, badly and suffering. Unfortunately, this reality exists, but there is much more" (P2 IT)*

*“****The fear of suffering****, already when they simply go for a mammogram. They are afraid of the cure because it itself creates suffering. This makes everything more frightening"(P3 IT)*

‘Sometimes they are ***obsessed*** *with the healthy diet. They almost think they have more information than the professional, but they do not adapt what they read on the internet to themselves, to their pathologies, to their history" (P3 IT)*

"The target on which we should work are those ***women who would normally adhere to visits****, but taken from assistance they* ***forget****" (P2 IT)*

“In my experience, the problem with ***women*** *is that* ***they think of others first****, then of themselves. They put themselves in the background.* ***Changing this mentality*** *should be the basis of the intervention. Everyone must understand that they need a moment for themselves"(P4 IT)*

‘If there is a cancer, ***it is a sign of death*** *so it is not worth going to the screening, anyway. Perceiving here also this more cognitive and emotional part that may be behind the adherence, or not, to the screening’ (P2 POR)*

‘The woman is also ***very afraid to find something****. And afraid to find it, she prefers not do palpation’ (P5 POR)*

‘Feelings of shame*! Have you ever encountered this? People do not want to expose themselves, do they? Some of them might have not come in terms with their own bodies even. Because this is an intimate part of the woman, exposing herself, isn't it? Maybe people from even more isolated, more rural backgrounds may feel more intimidated’ (P6 POR)*

Technology Preferences

What do you thing will be useful to suggest to us to have in mind when we design a mobile app that focused on breast cancer prevention?

The opinion of the experts participating in this particular focus group is that informal carer will be very receptive to creating a mobile application that will help them promote health. As for

the specific features that the mobile application should incorporate, the experts agree that it should be simple, realistic, user friendly and with optimistic messages.

The application should necessarily have a **network** (e.g. such as chats or groups) of informal carers who can relate and thus support each other, sharing fears and doubts. To this should be added **professional help, provided in a simple and direct way** to correctly direct the informal carers and make them feel supported also by the health personnel. There is a need for **humanized contact** between professionals and users. Finally, **information, useful contacts** of the **network of services**, including volunteering, which can help informal carers to manage their commitments and their time, giving them the opportunity to move away from home to dedicate themselves to their health.

The professionals gave some suggestions and priorities regarding the **application**:

- The main need is **the creation of a network** in which informal carers can relate, support each other, and share their fears, concerns and doubts. Indeed, informal carers often declare that they feel alone in front of their responsibilities; this would help to make them perceive united in difficulties. The technological elements of the **groups**, interactive **chats**, the possibility of scheduling visits and group meetings are suggested.
- The ability to **interact with professionals** for advice and information. The latter, however, must be given **in a simple and direct way**, with a non-technical language that is understandable to everyone.
- The creation of a **community local network** of **volunteer services'** contacts that can help them to manage their free time. **Useful information and numbers** on accompaniment, offices and services to make their search for formal support easier.
- A **motivational and emotional part** that regards adherence to practices, lifestyle, nutrition, meditation, exercise etc.
- Appointment or medical examinations reminders that allow the organization of information in a single application
- Recommendations for a healthier lifestyle, especially in terms of food and physical activity and that prevents diseases
- An application that encourages positive messages of encouragement and hope, in which doubts and opinions are shared
- Information about the functioning of the health system and other elements related to the prevention and treatment of breast cancer that allow, in a simple and interactive way, the clarification of the population
- A good articulation with the work carried out by superior entities so that two different and even confusing sources of information are not revealed

- Finally, positive messages of encouragement and hope

*'I would like to start with **simple and positive things** by downloading an application: my diet for simple things and then joining perhaps more complex ones **like mammography or mammography information**. I don't want to start with something more complicate. I don't like to download an application and be **in a negative mood**. I would like to start with something **more positive**! Always there is a possibility, we are all in risk to get sick from cancer or breast cancer for women etc. But I would like to start with a **positive note** and then get me the **test channel, in the procedure, the symptoms**'(P1 CY)*

*'...from previous experiences with mobile applications that we have made for the elderly was that when the apps are **personalize**, the elderly felt that it was especially for them and that they can modify it as they think it suits them. It is personally and they can modify it. I do it every day and every day is different. Everyone's schedule is different. It can be adapted to their needs' (P1 CY)*

I agree, I think it's very important that we get the message that we should take care of ourselves! So, if we are healthy, we will be able to take care of the person we care for. I think it's a very important message for informal carers!'(P2 CY)

*'...an easy to use application, an application that is **very useful and friendly** with **nice graphics with simple language, with colon, in short simple words, accessible**. Somehow like that. With tips. I would not like to see large paragraphs!'(P2 CY)*

*'...some **notifications from the app**... with a **positive message every day** or something that can be done by them. Maybe **an exercise to remind them** that they need to do an exercise every day or a reminder for an exercise or a proper diet.'(P2 CY)*

*'...to know that they will have **information from experts**. Ensuring them that what they say is reliable and can help them at any time. This is one of the best ways to handle stress' (P3 CY)*

*'I should also add that... we can **manage the fear of cancer disease** when we add aspects to the program and the application. To **give information about the disease and the treatment.** When someone gets sick is important to encourage them that there are new treatments, innovative treatments with fewer side effects, with much better results. So these can be added to encourage, empowered and motivate the patient with the right information so that they are properly informed and everyone did the right prevention (secondary/tertiary)' (P4 CY)*

*'All people **need to feel that we care for them**; we are **very close to them**, to **feel safe**. What people lack is the feeling of safety ... to feel that we are close to him during the therapy, whatever problem he has, and side effects of chemotherapy. He will be able to express her feelings and worries. We will be able to manage all this difficult problems together. My patients and I, all our team in general, we act/work as a team, half the work will be done by us and the other half by the patients. So let them feel that we are close to them!' (P6 CY)*

'An application that has ***direct communication with a team of experts****. Exactly! I want to talk to Stefanis, I will have direct contact with Stefanis. Have the comfort to do this thing' (P6 CY)*

'I agree to start with something ***enjoyable****, with the* ***right messages keep working****. We* ***build together****! Each time something different comes in, it gives a pleasant note and* ***optimism****. You want to join the app to see the next one, without ads! To keep the interest of the person' (P 6 CY)*

"It is much easier, as an informal carer, to have an application that says: "within two days or within one day" and she can plan her life… because you have to take care, you have to do many things. Since, when making an application, I think it would be a plus to have this ***reminder****" (P3 POR)*

"Recipes, recipes. The informal carer usually cooks, so this will take her to prepare the food, she will download it and will keep it. But if you have a recipe, a juice, we are going through this at home…" (P1 POR)

"the application suggests which ***foods can prevent cancer and so on*** *(…) Elements that favor a good quality of life, health" (P4 POR)*

"focus on the aspect "How can ***physical exercise improve your life****?" or "if you don't do it what can happen?, because saying that it's good just because it's good is how the history of tobacco is bad but the truth is that just saying it's bad, we have already seen, that it is not enough to make a person stop smoking. And, basically, the application almost gives me feedback if, effectively, within the foods that you choose, if it is actually the most appropriate food or not, or the so-called healthiest" (P6 POR)*

*"****A platform where dialogue is allowed*** *and, therefore, informal carer talking about patients, they share doubts, and with* ***health professionals , doctors, psychologists****, respond in good time to the doubts that are posed. So, maybe creating here, I don't know if it is possible, a forum" (P6 POR)*

"a kind of ***sharing platform between informal carers****" (P5 POR)*

"it is important to clarify how screening works in Portugal (…) the probability increases with aging, the probability of having breast cancer and, above all, in the most inactive people, breast cancer diagnoses are even more prevalent. It could be there, in terms of arguments for "why physical exercise can be good" directed towards breast cancer and positive news, especially relevant news. Do not disclose all information about breast cancer, because most of these people are people who will not have breast cancer. We are talking about a prevention perspective and not a treatment perspective" (P2 POR)

"also some connection with the Liga here, as an entity that does the screening because if I have an application on breast cancer prevention, on screening, for what I understand, and if I already I received a letter inviting me to do the screening on this day, maybe my application

should give me a reminder that I have already scheduled my mammogram on the mobile unit (...) there must be a good marriage" (P2 POR)
'Why not, from time to time, or I don't know if once a month is a lot, maybe it is a positive message "prevention is always worth it, don't forget to take care of yourself" (P2 POR)

Barriers for using mobile application

According to professionals, although all views converge that this is an interesting application, they are on alert for difficulties that may arise in the use of the mobile application.

Resistance to use the technology

'I think they are positive about an application. Although there may be one kind of Resistant to the use of technology for some individuals' (P1 CY)

Elderly people not familiar with technology

'From my experience with older people, which was most difficult situation, because they are not so familiar with technology, that they will be very receptive because will be considered as a helpful instrument for both of them: the patient and the informal carer as well' (P1 CY)

Appendix I: DEMOGRAPHICS FOR INFORMAL CARERS PARTICIPANTS

Informal Carers - IO1 Focus group – Demographics Questionnaire

Date__________ **Place**____________________

Questionnaire number:________

Dear participant,

Before starting the focus group, we kindly ask you to provide some general information about you and the person you are caring for. All the information that you provide will be treated anonymously and used for the aims of the Prolepsis project according to the privacy rules in force (*please note*: *each partner should refer to the relevant national regulations).*

(check [✓] all that apply)

1. **Age in years:** ____________
2. **Please specify what is your marital status at present:**

Married/Cohabiting	1
Separated/ Divorced	2
Single	3
Widowed	4

3. **What is your Smoking Status?**

Never Smoked	1
Ex- Smoker	2
Former Smoker	3

4. **Alcohol Use**

Not drinking at all	1
Drinking regularly (less than 1–2 glasses per day)	2
Heavy drinking (more than 3-4 glasses per day)	3

5. How often you do Physical exercise?

Not at all	1
One to two times a week	2
Three to four times a week	3

6. How many meals do you typically eat in a day?

1-2	1
2-3	2
3 or more	3

7. How many Snacks do you typically eat in a day?

1-2	1
2-3	2
3 or more	3

8. Which is your Body Mass Index

High	1
Normal	2
Low	3

if you don´t know please indicate your tall____--and weight):____________________

9. Are you in compliance with cervix cancer screening guidelines?

Yes	1
No	2

10. Do you perform breast self-exam regularly and as your doctor/health professional recommendations?

Yes	1
No	2

11.Do you have a specific disease?

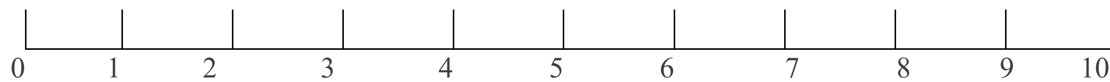
Yes	1
No	2

Specify………………………………………………………………………

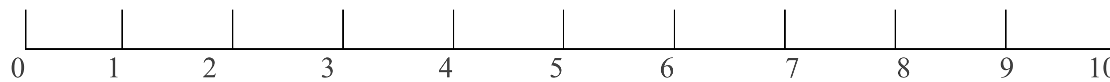
12. Do you take any medications for this disease?

Yes	1
No	2

13. How do you evaluate your general quality of life?



14. How do you evaluate your general health?



15. What is your educational level?

No education	☐ 0
Primary education (1st cycle)	☐ 1
Lower secondary education (9th grade)	☐ 2
Higher secondary education (12th grade)	☐ 3
Tertiary education (university or further education level)	☐ 4

16. **Please indicate your present working situation:**

Retired	☐ 0
Still working full time	☐ 1
Still working part time	☐ 2
Unemployed	☐ 3
Housewife	☐ 4
Other *(please specify)*:____________________	

17. **Do you have any children?** ☐ yes ☐ no

If yes, how many?_______

18. **What is your relation with the person you care for?**

Spouse/Partner	1

Sibling	2
Daughter/Son	3
Daughter/Son-in-law	4
Grand-son/Grand-daughter	5
Nephew/Niece	6
Other relative (please specify: ________________________)	7
Friend	8
Neighbour	9
Other non-relative	10

19. **How old is this person? _______ years-old**

20. **How long have you been providing assistance to him/her?**

Years ________ or Months________

21. **On average, how many hours per week do you assist the person you care for?** ________

22. **Where do you and the person you care for usually live?**

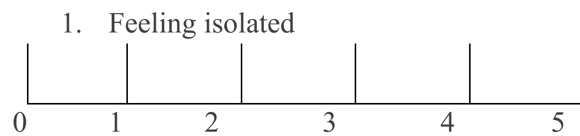
In the same household	1
In different households but the same building	2
Within walking distance	3
Within 1 hours drive/bus or train journey	4
Over 1 hours drive/bus or train journey	5

23. **How dependent is the person you care for?**

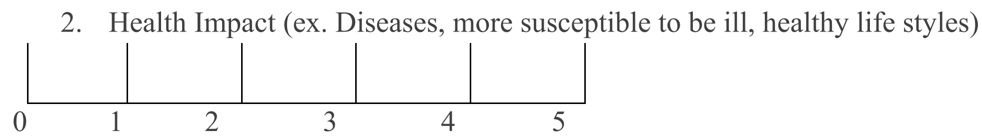
Severely Dependent – Unable to carry out most activities of daily living, without help (e.g. feeding themselves, or going to the toilet)	4
Moderately Dependent – Able to carry out some basic activities of daily living (for example, bathing, feeding, dressing) but unable without help to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework)	3
Slightly Dependent – Able to carry out most activities of daily living, but requires help with some instrumental activities (e.g., shopping, cooking, housework, etc)	2
Independent – Able to carry out most activities of daily living, but may need some help occasionally	1

24. Please characterize the intensity of the impact of the caring responsibilities (scale 1 - no impact at all to 5 – extreme impact):

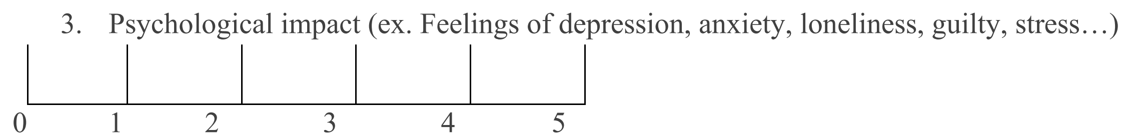
1. Feeling isolated



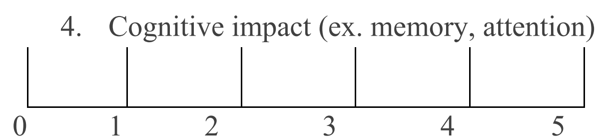
2. Health Impact (ex. Diseases, more susceptible to be ill, healthy life styles)



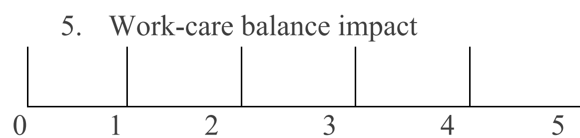
3. Psychological impact (ex. Feelings of depression, anxiety, loneliness, guilty, stress…)



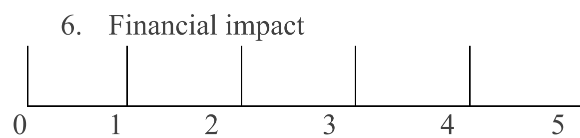
4. Cognitive impact (ex. memory, attention)



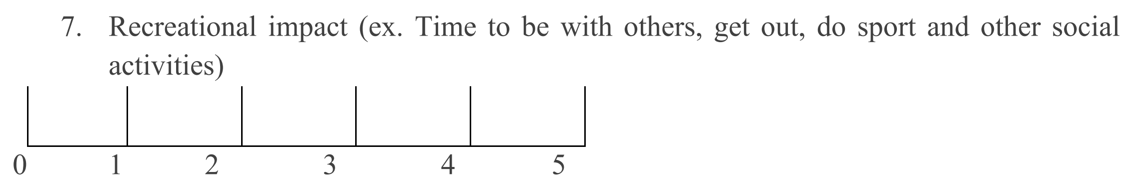
5. Work-care balance impact



6. Financial impact



7. Recreational impact (ex. Time to be with others, get out, do sport and other social activities)



25.What is more difficult to you in caring for your loved one (please choose the 3 most difficult to manage)?

- ☐ Treatments
- ☐ Nutrition
- ☐ Self-image and hair loss of the person you care
- ☐ Transports
- ☐ Financial issues
- ☐ Emotional distress
- ☐ Health promotion
- ☐ Take care of your self-care and/or satisfy your needs and preferences

26. Did you feel the need to ask support outside the family?

Yes	1
No	2

27. Do you feel yourself very worried and anxious with the possibility to have breast cancer?

Never;	1
Rarely;	2
Sometimes	3
Often;	4
Almost every time	5

28. **Do you do breast self-examination?**

Yes No

29. **How often do you do Self - Breast Examination (SBE) for checking breast cancer symptoms?**

Never	1
Monthly	2
Every 6 months	3
Every year	4

30. **How often do you do Mammography Examination?**

Never	1
Every year	2
Every 2 year	3
Over 2 years	4

31. **Your role as a carer affects the frequency of the Self-Breast Examination**

Yes No

32. **Do you think are you in a high risk of getting breast cancer**

Yes No

33. **The health habits like smoking, nutrition, have any impact on occurrence of illness?**

Yes No

34. **Do you own a smartphone?**

Yes	1
No	2

35. **How often do you use it daily?**

> 2 hours;	1
1 to 2 hours	2
<1 hour	3

36. **Do you use technology for:**

Exercise	1 Yes
	2 No
Work	1 Yes
	2 No
Information seeking	1 Yes
	2 No
Communicating with family and friends	1 Yes
	2 No
Entertainment	1 Yes
	2 No
Monitor health –related behaviours	1 Yes *Which ones….* ☐ Tobacco consumption ☐ Alcohol consumption ☐ Physical exercise ☐ Body weigh ☐ Diet ☐ Relaxation and mental health promotion ☐ Other health issues ____Specify____
	2 No

37. Have you installed an app for the prevention of breast cancer in the last 3 months?

Yes	1

No	2

If No:

38.Would you be interested to use a free mobile app to help you prevent breast cancer? (1- not interested to 5 – very interested)

0 1 2 3 4 5

39.What kind of services could be useful for you in this application? 1-not useful to 5-very useful)

Monitor Health information

0 1 2 3 4 5

Social strength (learn and support with real life stories of people that share their experiences, tips and inspire others)

0 1 2 3 4 5

Personalized information and notification for Health Promotion

0 1 2 3 4 5

Store Files (easily access to documents securely stored on your mobile)

0 1 2 3 4 5

Access to entertainment

0 1 2 3 4 5

Access to healthy life styles activities promoted by health care team and in the local municipally

0 1 2 3 4 5

Access to challenges to promote behavior changes towards breast cancer prevention

0 1 2 3 4 5

Access to new research about breast cancer treatments and prevention

0 1 2 3 4 5

Communication with healthcare professionals

0 1 2 3 4 5

40. **Would you be interested in participating in the evaluation of a mobile app for breast cancer prevention?**

Yes	1
No	2

Thank you for kindly participating in this questionnaire!

Appendix II: FOCUS GROUPS GUIDE – FOR INFORMAL CARERS

<table>
<tr><td>INTRODUCTION
5 min intro + 10 min (ice-breaking questions)</td><td>• Welcome
• Introduction of moderator, assistant moderator and of the participants
• Presentation of the project and purpose of focus group
• Ground rules</td></tr>
<tr><td colspan="2">Section 1: Mapping the needs, attitudes, knowledge, believes and perceptions of informal carers

Investigate knowledge and perceptions on educational and training opportunities or barriers in promoting prevention</td></tr>
<tr><td>Topic</td><td>Questions</td></tr>
<tr><td></td><td></td></tr>
<tr><td>Knowledge</td><td>What do you know about breast cancer?

Do you think is important to do Breast Self-Examination?

Do you know how to perform a Breast Self–Examination?

How often do you perform a Breast Self-Examination?

When do you think you should consult a health professional?</td></tr>
<tr><td>Perceptions</td><td>Do you believe that screening could help?</td></tr>
<tr><td>Beliefs</td><td>Do you believe that there is a risk for you to become ill from breast cancer?

Do you believe that the health habits like smoking, nutrition, have any impact on the occurrence of illness/breast cancer?</td></tr>
<tr><td>Attitudes</td><td>What is your attitude towards Breast-Self Examination?

What is your attitude towards Clinical Breast Examination?

What is your attitude towards mammography screening?</td></tr>
</table>

Barriers	What do you perceive as barriers for doing a self examination? (Looking back) have you missed (or avoided) any screening appointments?
Benefits	Do you know the benefits of early recognition of breast cancer?
Section 2: Personal Involvement	
Topic	**Questions**
	Do you feel that your caregiver role has somehow influenced your life? Has your caregiver role influenced your screening practices in any way? (Positively or negatively?)
Section 3: Significant Others Experiences	
Topic	**Questions**
	Are experiences described by your relatives in some way affecting you?
Section 4: Motivator Factors	
Topic	**Questions**
	What are the factors that drive you to engage in breast self-examination?
Section 5: Technology Preferences	
Topic	**Questions**
	Which would be from your point of view the desired features in a cancer prevention application (some examples to explore: health behavior tracking? Use of reminders? Tailored information? Reward and challenge system? Are you familiar with mobile APPs related to illness prevention? Would be useful to have a storing of personal data but keeping personal health data private and secure, but easily access by phone anytime you need? Which factors can influence in your perspective the use of this app? (some examples: quality of the user interface, peer influence, easiness of use, level of feedback, interactiveness)

Appendix III: DEMOGRAPHICS FOR HEALTH CARE PROFESSIONAL

Health care Professional - IO1 Focus group – Demographics Questionnaire

Date___________ Place______________________

Dear participant,

Before starting the focus group, we kindly ask you to provide some general information about you. All the information that you provide will be treated anonymously and used for the aims of the project according to the privacy rules. Please provide your information by circling the item that best describes you or your situation or by writing your answer in the space provided.

1. **Gender** 1 . Male 2 . Female

2. **Age:** _____________

3. **Highest level of education completed (please use space provided to explain into what domain)**

Diploma	1
Bachelor's degree	2
Master's degree	3
PhD	4

4. Occupation………………………..
Years in current position…………………………..
Years of total experience ……………..
If less than a year specify the number of months ……….

5. Current type of work
1. Full time 2. Part time

Thank you for kindly participating in this questionnaire!

Appendix IV. FOCUS GROUP GUIDE FOR HEALTH CARE PROFESSIONAL

INTRODUCTION 5 min intro + 10 min (ice-breaking questions)	• Welcome • Introduction of moderator, assistant moderator and of the participants • Presentation of the project and purpose of focus group • Ground rules

Section 1: Mapping the needs, attitudes, knowledge, believes and perceptions of informal carers Investigate the educational priorities about Breast Cancer and Breast Cancer prevention including screening controversial areas as these might echo potential threats to promoting BC screening in practice.	
Topic	**Questions**
Professionals knowledge, views	What do you think are the educational priorities that should be set in a breast cancer education program? What should be included in a breast cancer educational program in order to motivate informal caregivers to adopt breast cancer prevention behaviors?
Barriers	What do you believe that may perceived as barriers in relation to their role by informal caregivers for doing a Breast Self - Examination? What are the potential fears for adopting breast cancer prevention behavior in practice?

Section 2: Technology Preferences	
Topic	**Questions**
	What do you thing will be useful to suggest to us to have in mind when we design an app focus on breast cancer prevention?