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Cancer prevention, early detection, and screening:

EU citizen perceptions and experiences

Report on focus groups with citizens in six EU Member States to support the implementation of the EU Cancer Mission

Research and Innovation

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EUROPEAN COMMISSION

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Report on focus groups with citizens in six EU Member States to support the implementation of the EU Cancer Mission

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Executive Summary

Background

The EU Cancer Mission has set the goal to improve the lives of more than 3 million people by 2030 through prevention, cure and for those affected by cancer including their families, to live longer and better [1]. To learn about what citizens find important, a series of focus groups were organised with citizens in six EU Member States: Bulgaria, Czechia, Finland, France, Lithuania, and Malta. The focus groups concerned discussions about cancer awareness, prevention, early detection, and screening.

Perceptions regarding cancer

The focus groups indicated that cancer was perceived as a frightening disease that could happen to anyone. The fear of a cancer diagnosis and the taboo associated with some cancers could prohibit people to visiting or contacting a doctor. The group was suggested to explain that cancer is not a death sentence and to inform people on what could help prevent cancer.

Perceptions regarding the prevention of cancer

Participants indicated that healthcare professionals are a key source of information. They also emphasised the importance of education about cancer risks and prevention as part of the school curriculum and addressed the importance of accessible and reliable information. Campaigns should express hope and focus on what to do to prevent cancer. Several cancer risk factors were discussed, including sun exposure, tobacco, alcohol, environmental factors, diet, physical activity, and stress. Participants referred to a lack of awareness on how these factors can cause cancer and on how to change their behaviour to avoid exposure to risks and promote a healthier lifestyle. Several participants also discussed the risk of developing cancer due to a hereditary predisposition, despite a healthy lifestyle.

Perceptions regarding early detection and screening

Participants were largely aware of the importance of checking and monitoring one's body to detect any changes. Most participants were also aware of screening programmes to detect cancer at an early stage. Reasons for not participating in screening programs, included shame in discussing irregularities and the fear of being diagnosed with cancer. Another barrier was the distance to screening centres for people in remote areas. It was suggested to offer mobile screening facilities, and/or to include cancer screening via general and occupational health practitioners. Participants also mentioned that better information on screening programs is needed to increase participation rates. Information should enhance the understanding of screening and what a screening test entails. Health professionals have an important role to play to better informing citizens on screening programs and to promote open discussions to reduce shame and fear. Still, governments were considered to be the main source of information, for instance via (social media) campaigns.

Main recommendations

The insights from this study, although based on focus groups with a limited number of EU citizens, underline the importance of improving information and communication on cancer prevention and early detection and screening for EU citizens. More and better actions are needed to address barriers and support citizens in preventing cancer, with actions and initiatives that consider different levels of motivation and beliefs of the population and the wide array of aspects that could hinder preventive and early detection measures.

1. Background

The EU Cancer Mission has set the goal to “improve the lives of more than three million people by 2030 through prevention, cure and for those affected by cancer including their families, to live longer and better”.[1] Aligned with the Mission, Europe’s Beating Cancer Plan represents a political commitment to take action against cancer, by focusing on inequalities in cancer awareness, prevention, diagnosis, and care.[1, 2, 4]

Both the EU Cancer Mission and Europe’s Beating Cancer Plan have indicated that cancer prevention is a high priority, because it can minimize avoidable harm to citizen’s wellbeing and it is the most cost-efficient long-term cancer control strategy.[2] Likewise, the detection of cancers at an early stage is a high priority of the Mission and the Cancer Plan to reduce cancer mortality and morbidity [3] and improve patient outcomes. Early detection and early diagnosis of cancers can be achieved by identifying asymptomatic (pre-)cancers through screening, either of predefined populations (programmatic screening) or of individuals with an increased risk of cancer as identified within the healthcare system or at their own request (opportunistic screening).[4, 5]

Citizen engagement activities have been considered highly important in all phases of the Mission development and implementation, to ensure that the knowledge, needs, preferences, and potential of EU citizens are considered when developing interventions and actions to prevent and fight cancer.[1]

In developing and implementing actions to improve cancer prevention and early detection within the EU, the Mission aims to get citizens’ feedback on existing and potential preventive measures and use their feedback to tailor preventive measures to the needs of various population groups.[1] It has been shown that citizens can draw from experiences and observations from their personal networks and provide valuable inputs on cancer prevention and early detection.[4, 6]

This report describes a series of focus groups that were held as part of citizens’ engagement activities of the Mission on Cancer, with the aim to get a better understanding of how citizens in several EU Member States perceive cancer risk, prevention, and screening and what services for screening and early diagnosis they can access.

2. Methods

In this chapter we provide a brief description of the methods used for the focus groups and an overview of the participants in the focus groups. More details on the methods used for the organisation of the focus groups can be found in Annex 1.

2.1. Organisations participating in the focus groups

Local public health and/or academic institutions supported the organisation of focus groups in six countries, as described in Table 1.

Each organising partner was responsible for assigning a moderator and co-moderator to facilitate the discussion and finding a venue to host the focus group at a convenient location for the participants and the moderators. They used their network and their own recruitment strategies to invite participants. The EUHealthSupport consortium coordinated the focus groups, guided the local moderators, and provided information materials for participants. They also provided a focus group discussion guide for the moderators and an informed consent form to assist the local organising partners.

All focus groups took place in-person from April to October 2022, lasted approximately 2.5 hours and were held in the local language to promote a comfortable atmosphere and allow participants to express themselves freely.

All countries hosted one focus group except for Czechia, where two focus groups were held, one in Prague and one in Brno, to ensure that sufficient participants attended. In two countries (France and Finland), the focus groups took place with targeted populations. The French focus group aimed to target young women (aged 18 – 30 years) from disadvantaged neighbourhoods in the Hauts-de-France region; the Finnish focus group targeted senior citizens (aged above 70 years) in North Karelia because it is a region that has previously been successful in implementing a large-scale prevention strategy on cardiovascular diseases [7, 8] where it was believed that senior citizens that had experienced the results of this project could provide insights on what is necessary for cancer prevention in their region. Further details are described in Annex 1.

The local organisers provided the transcript of the meeting and the EUHealthSupport team was responsible for the translation of the transcripts. EUHealthSupport researchers analysed the English-language transcript using thematic coding and synthesised the main findings in a summary (see Annex 2). This summary was shared with the moderator of the focus group to confirm that the main messages and results were accurate and well interpreted.

Table 1. List of countries and partner organisations planning the focus groups.

Country	Partner Organisation	Focus Group Date, Place
Bulgaria	Bulgarian Sports Development Association	8th May 2022, Sofia
Czechia	National Institute of Public Health (SZÚ)	22nd September 2022, Prague and Brno
Finland	University of Eastern Finland	11th August 2022, Joensuu
France	Centre Oscar Lambret	1st October 2022, Lille
Lithuania	Hospital of Lithuania University of Health Sciences, Kauno Klinikos	17th October 2022, Kaunas
Malta	University of Malta	24th September 2022, Malta

2.2. Participants

Each focus group, except for France, consisted of 7 to 15 participants of different genders, ages, socio-economic backgrounds, and place of residence. Participants did not need to have personal experience with cancer. In France, the organisers were able to reach and invite more than 20 women, however, only 3 of these participated. Organisers have reported that young citizens living in Lille are difficult to mobilise and motivate to participate, even in other health initiatives such as PREVENGYN.[9] Table 2 below summarises the characteristics of the participants in each country. Further details are provided in Annex 1.

Table 2. Characteristics of Focus Group Participants per Country

Country	Nr of partici-pants	Age range	Gender	Place of residence	Profession
Bulgaria	10	32 to 52	5 Female 6 Male	City	All employed (various sectors)
Czechia, Prague	6	28 to 61	4 Female 2 Male	1 Rural area 5 City	6 Employed professionals
Czechia, Brno	6	17 to 45	4 Female 2 Male	3 Rural 3 City	4 Students 2 Employed professionasl
Finland	14	57 to 80	2 Female 12 Male	4 Countryside 10 City*	All retired
France	3	25 to 26	3 Female**	City	2 Students 1 Stay-at-home mother
Lithuania	10	18 to 65	7 Female 3 Male	8 City 2 Village	2 High-school education 5 University/Higher education 1 Vocational education 2 Other
Malta	9	31 to 76	6 Female 3 Male	1 City 8 Towns and Villages	4 Employed 3 Retired 2 Housewives

*Small cities with a low population density.

** We aimed for a difficult to-reach-group of women living in disadvantaged neighbourhoods and with often a minority background.

3. Results

In this chapter, we present the main topics and findings as discussed during the focus groups discussions. We present the results in 3 main sections: perceptions regarding cancer, perceptions regarding prevention of cancer, and perceptions regarding early detections and screening. Further details and results per country can be found in Annex 2.

3.1. Perceptions regarding cancer

The focus groups commonly started with a discussion on general perceptions with respect to cancer. It was also discussed if cancer is a topic that is easily talked about with friends and family and with healthcare professionals. From these discussions a number of main themes could be distinguished, as described below.

Cancer as a common disease

In several focus groups it was mentioned that people know cancer is a common disease. In a couple of focus groups (Czechia, Lithuania), there seemed to be a general conception that cancer could happen to anyone and that there is only so much that you could do to prevent it. In the Lithuanian focus group in particular, some participants had the perception that environmental factors and the stressful life that people lead, is something that can cause cancer, but that is out of people's hands. Many participants of the different focus groups had someone in their network who has or had cancer.

Anxiety about cancer

Participants of the focus groups often thought that people are afraid of being diagnosed with cancer. This was most explicitly discussed in one of the focus groups that was held in Czechia. In that focus group, participants stated that a cancer diagnosis was considered by many to be a death sentence. The fear of a cancer diagnosis was thought to prohibit people from visiting a doctor. In addition, it was stated that many people are afraid of doctors and might therefore not visit a doctor for early symptoms of cancer.

In several focus groups, how receiving information about cancer could scare people was discussed. In the Lithuanian focus group, it was expressed that cancer fundraising commercials and campaigns for cancer foundations can make people afraid of getting cancer. In the focus groups in Czechia and France, it was discussed how information about cancer could scare people instead of making them aware of what could be done to prevent it or detect it in an early stage. It was suggested that information about cancer should explain that it is not a death sentence, but that it is a disease that could be prevented and treated. In the Maltese focus group on the other hand, it was stated that people seem to be indifferent about cancer and that people overall do not take cancer risks and prevention seriously.

Talking about cancer

One of the focus groups that was conducted in Czechia indicated that people's fear for cancer might make it difficult for people who have or had cancer to talk about it. Participants of that focus group felt that there was a taboo in their society to talk about cancer. Also, in the Lithuanian focus group participants discussed that it can be very difficult for people to talk about cancer, especially with persons who have (had) cancer. This was mainly put forward by older participants. Yet, the younger participants in focus group stated that nowadays people talk more easily about cancer.

Differences between generations were also reflected in the Finnish focus group, where it was mentioned that cancer used to be a taboo topic, but that this has changed over the

years and that it is now more openly discussed within social networks. Discussion groups were regarded as helpful to further open up the discussion about cancer.

Cancer was not commonly discussed with general practitioners among the young women that participated in the French focus group. It was suggested that perhaps other healthcare professionals, like pharmacists, could provide information on cancer, thus putting less burden on general practitioners. In this focus group it was also mentioned that some types of cancer, in particular breast and cervical cancer, can still be a taboo topic and therefore difficult to discuss.

3.2. Perceptions regarding the prevention of cancer

Health information and information sources about cancer prevention

Participants mentioned several sources of information on cancer prevention. In most countries, participants indicated that for them the best sources of information about cancer and prevention are doctors and other healthcare professionals. They might look up health information online but then discuss this information with a health professional. However, the participants in France mentioned that they got their information from social media and other internet resources such as the 'Doctissimo portal'. Besides the internet, participants in Bulgaria also referred to what they 'have heard from others' as their sources of information on cancer.

Prevention and information campaigns/education

In all of the six focus groups, participants emphasised the importance of education about cancer, risks and prevention to young people. This should start at a young age, to make them aware of the effects of alcohol and tobacco, unhealthy food and sun exposure on their health. Besides making young people aware of what raises the risk of getting cancer, participants also emphasised that it was important to explain how to prevent cancer through lifestyle and health screenings.

Education, including in schools, was considered key to help highlight cancer risk factors and stress the importance of avoiding those. Prevention should be part of the school curriculum according to some participants, and healthy behaviours such as sun protection and being active should be taught to children. Bulgarian participants also pointed out that they believed parents need to have a more educative role of on what healthy eating is, what are considered healthy behaviours, what to avoid, or how to minimise risk factors. Participants in France also mentioned that it is important that people get educated about HPV and the risk for cervical cancer, as part of sexual education.

Participants agreed on the importance of having widely spread and accessible information and campaigns on cancer prevention (and not only during the awareness-raising months, as mentioned in the French focus group). As participants agreed that awareness raising was key to make citizens more aware and concerned of the risks and on taking preventive steps to protect themselves, they expressed that there is a strong need for reliable and verified health information from the government (Ministry of Health) or in the media. In the focus groups in France and Czechia, it was stressed that prevention campaigns should not scare people about cancer, but rather express that there is hope and focus on what people can do in practice to prevent cancer. Simpler messages, especially when it comes to healthy diets, would help reach a younger audience.

In the Maltese focus group, participants felt that there is a lack of public health information on cancer, while it was very important for citizens to prevent cancer. In the focus group that was held in Bulgaria, participants mentioned that besides a lack of information on prevention, a lack of basic medical knowledge among the population, and a lack of prevention initiatives hindered people's involvement in cancer prevention.

Healthy behaviours and risk factors

Sun exposure

Participants in all countries were concerned about sun exposure as one of the main contributing factors towards developing cancer. Participants in Finland described seeking shade and wearing clothing that covered their skin to protect themselves against sun exposure. In Malta, participants said that while quite some adults take protective measures such as using sunscreen and hats against sun exposure, many do not. However, there is more concern for protecting children. In Bulgaria, participants mentioned that the public is not aware that sun exposure heightens the risk for cancer, and practical guidelines on how to avoid risks such as the sun are missing, as they have noticed that people do not use hats or seek the shade.

Tobacco and alcohol

In all countries, participants mentioned smoking as a risk factor for cancer. However, once one has started smoking, they don't quit so easily, despite knowing the negative effects or even having loved ones who are affected by cancer due to smoking. That is why participants in all countries felt that education on healthy behaviours should start at a young age. Participants were not always aware that alcohol, also in moderate amounts, can cause cancer. Participants in France mentioned they are aware that alcohol can be harmful, but they felt those effects were trivialised as drinking alcohol is part of French culture.

Policies to limit the use of tobacco and alcohol, such as taxation and labelling were thought to have limited to no effect on reducing use in (heavy) users. Participants believed that people who already consumed alcohol and tobacco would continue to do so despite higher prices or graphic pictures. However, they did think that such measures deterred the younger generations from smoking and/or drinking alcohol.

In Malta, participants thought the application of some warning label on bottles containing alcoholic beverages was a good idea, but they also raised doubts about whether consumers would even look at it. Participants in Finland pointed out that taxing alcohol and tobacco could promote the production and circulation of uncontrolled goods, introducing a black market. A participant in France suggested that, as with tobacco products, there could be spaces dedicated only to selling alcohol, which could work to reduce alcohol consumption; but at the same time, they wondered if such selling points would become a profitable business and this would have the opposite effect.

Stress

Participants in Bulgaria, Finland, Czechia and Lithuania mentioned stress as a risk factor for cancer. The participants in Bulgaria mentioned stress related to the number of serious problems that people struggle with in their daily life, which makes an (un-)healthy lifestyle less of a priority. Participants in Finland equally pointed out the effects of stress on lifestyle being a contributing factor that could trigger the onset of cancer.

The environment

The environment was discussed in various ways in relation to cancer, as a risk factor for cancer or a medium through which people might be more exposed to cancer risk factors. Participants in Bulgaria mentioned stress and (air) pollution as risk factors for cancer. Toxic fumes were also seen as heightening the risk of developing cancer by the Maltese participants. Participants in Lithuania stated that even though as an individual you try your best to have a healthy lifestyle, environmental factors make it difficult to prevent cancer.

However, the environment could also be seen as a protective factor. In Malta, participants believed that a green environment with many trees could help prevent cancer, as it provides fresh air and shade, thereby preventing people from being exposed directly to the sun.

Diet and exercise

Participants in all countries indicated that they knew it was important to have a healthy diet and to exercise to benefit one's health and help prevent cancer. In the countries where this was discussed in detail (Malta and Finland), a diet with fruit and vegetables was mentioned as healthy, while red meat was mentioned as increasing the risk for cancer, as well as processed foods and products that had been sprayed with pesticides. However, some participants noted that despite this awareness they have not changed their dietary or exercise habits.

Most participants in Finland, where the average participant age was 73 years, felt that they were too old to change their habits and it was not going to make much of a difference now. In the other countries, (personal) habits and culinary customs were mentioned. In Czechia, a participant mentioned being aware of the need to eat healthy food but that this can be expensive and that it could explain the poor-quality food that people eat that affects people's health.

Exercise was considered important for the prevention of cancer, but participants did not always specify whether they exercised. When they did not exercise, they mentioned that they didn't have the time or had caring responsibilities (Czechia, France, Malta), that they did not enjoy exercise (France), or felt too unfit (Finland).

HPV vaccination

HPV vaccination was discussed in two focus groups, in Czechia and France (in France participants were young women recruited through a gynaecological cancer prevention program. Participants seemed to know about the existence of the HPV vaccine but were unsure about its effectiveness (Czechia) or were not familiar with the details (France). One participant in France tried to get vaccinated but encountered barriers because of her age.

Other

In four countries (Finland, Malta, Lithuania and Czechia) participants also discussed the possibility of developing cancer due to a hereditary predisposition, despite having a healthy lifestyle.

3.3. Perceptions regarding early detection and screening

Early detection and cancer screening programmes

In general, participants across focus groups in Bulgaria, Czechia, Finland, France, and Lithuania showed awareness on the importance for checking and monitoring one's body to detect any changes on it. Some stressed out that early detection and taking care of one's health is one's own responsibility. Most participants showed some knowledge about some symptoms that could be checked for cancer. Participants in Czechia and France also expressed that they feel that they can address and discuss these symptoms with people around them and with their health practitioners.

However, and as an example, regarding breast palpation, female participants in France mentioned that although they have been instructed on how to check their breasts, they remained uncertain on how to realise what could be an abnormality. The experiences of

some of these women suggested that, although they have been taught about self-palpation, questions remain and that they didn't feel well informed overall.

As well, participants in Lithuania discussed about symptoms that could indicate cancer, but also acknowledged that these could also be symptoms for another disease.

Cancer screening programmes and participation

Most participants showed awareness and knowledge about the existence of screening programmes. Still, there were some participants, for example in France, that showed no knowledge or awareness on these screening programmes. Across countries and participants, most agreed that screening programmes are important to detect cancer at an early stage. Participants in Finland mentioned that participating in these screening programmes can give a sense of security that nothing goes unnoticed, and that one can get treated early if a diagnose is confirmed.

There were several participants (some senior participants and some female participants in Czechia, Finland, France, and Lithuania) that reported having participated in screening programmes and regarded the experience as a positive one. However, senior participants in Finland wondered about the frequency and the age limits for participation in cancer screening. These participants believed that screening programmes should have no age limits or that the age limits should be less restrictive (starting at an earlier age and ending at a later age).

Furthermore, in Czechia and Finland, some of the participant's health practitioners discussed the results of their test with them. However, some other participants in Finland and France reported that their health practitioners did not discuss the results with them or not thoroughly enough for them to understand the implications or understand cancer screening better, and rather directed them to information portals. Thus, participants stressed the importance of communication on screening, the results of screening tests, and cancer by health professionals to increase awareness and participation, and to increase understanding of what early detection and screening entails.

Most participants discussed the possible reasons for the low participation in screening programmes in their countries. Some participants in Bulgaria and France mentioned that awareness is low in their countries and that some have been screened due to family history (opportunistic screening) without much knowledge on the opportunity of getting screened. Some participants in Czechia and France were aware of the existence of invitation letters to participate in screening programmes in their countries and regarded them as helpful. Most participants agreed that a wider spread of information is needed to raise awareness on the exitance and importance of screening programmes and what the actual screening tests entail since currently this lack of information on these aspects may be hindering participation. For example, participants in Lithuania expressed that it could be more difficult to involve men in screening programmes due to the fear of getting tested by an invasive procedure; therefore, more information on how tests are being done are deemed necessary. Participants in Czechia and Lithuania mentioned that health practitioners should play a stronger role in communicating about these programmes and even reminding people about the opportunity to participate. Some participants in Czechia also suggested that (financial) incentives or having a day-off to participate in screening could promote and improve participation.

Other reasons shared by participants in Czechia, Finland, Lithuania, and Malta contributing to the low participation in screening programmes included the element of shame of discussing irregularities to their health professionals and participating in the screening and an element of fear of getting tested (what the test entails) and having a diagnosis confirmed.

Access to screening programmes

Participants discussed accessibility of screening programmes and mentioned some barriers that people can face to get screened. One common barrier shared across focus groups (Bulgaria, Czechia, Finland, and Lithuania) was the distance to centres where screenings take place. These centres can be difficult to reach for people living in remote areas since traveling to healthcare facilities and/or screening centres can be burdensome for some people. The organisers of the focus group in France, mentioned that in Lille, it is difficult to mobilise citizens from underserved neighbourhoods into participating in health initiatives, such as gynaecological prevention programmes like PREVENGYN.[9]

In addition to distance to health facilities, some participants in Bulgaria mentioned the shortage of healthcare professionals in addition to the impact of the COVID-19 pandemic that has delayed cancer screening, diagnosis, and treatment of cancer. To improve participation and access to screening, some participants in Finland and Lithuania suggested offering screening on location on a particular day, e.g; mobile screening facilities. Better services could be provided by general and occupational health practitioners by expanding their medical training to include cancer screening. Finnish participants also mentioned the need to expand funding to improve accessibility to screening programmes.

Information sources about early detection and screening programmes

Participants agreed that getting educated about cancer screening is important. Some participants in Bulgaria, Czechia, France, and Malta agreed that information should be provided at an early age (e.g., adolescence) and, thus, could be provided at schools.

Some participants in Czechia and Lithuania acknowledged that sometimes the information in the media on early detection and screening might not be accurate or could be misleading. Therefore, these participants agreed that the government and the Ministry of Health could do better in providing and spreading information about cancer screening. The Ministry of Health should be the main source of information and it should also verify the information that is (already) available in the media. They also believed that health professionals should be the main source of this information and that it could promote open discussions about health and reduce shame and fear in seeking healthcare and participating in screening programmes. In Malta, participants agreed that the government has not done enough to provide information to the population about screening and early detection.

Participants in Bulgaria, Czechia, France, and Malta also suggested the use of campaigns to further inform the public about cancer and screening. Some participants in Finland, France, and Lithuania mentioned that an increase in awareness and campaigns that include the participation of social figures (e.g., celebrities, influencers) could reduce the shame surrounding early detection and cancer screening and help raise awareness in getting screened.

Participants in France also mentioned that it is important to consider how campaigns are delivered to prevent misconceptions. For example, they discussed that the colour blue in ‘Blue March’ (campaign for colorectal cancer) could be misleading since people might think that it is a campaign directed only to men. Participants mentioned that (verified) information could be widely spread by using the media and social media for this purpose. They supported the use of invitation letters, text messages, emails, or the use of an app to communicate with the public and remind them about screening opportunities to encourage participation.

4. Reflections and main recommendations

4.1. Reflections on the study

In this section we reflect on the main outcomes of this study and provide recommendations that could support the implementation of the EU Cancer Mission.

Firstly, an important finding is the common perception in some countries that a cancer diagnosis is a death sentence. This perception might prohibit people from acting when having early symptoms of cancer and it is therefore of the utmost importance to inform people that cancer is a disease that is preventable and treatable. Messages that offer people practical and positive information is key to make clear that people can do something to prevent cancer or to detect it at an early stage.

In addition, it was found that although most people seem aware of the major risk factors for cancer, several participants felt that there is little that can be done to prevent it and that it could happen to anyone. This perception might make it more difficult to stimulate people to avoid risk factors. However, when addressing risk factors that require a behavioural change in the population, it is important to consider the different motivators and beliefs of the population. More information and education that addresses people of all ages, including young people and children, are necessary to stress that cancer is preventable and that changing unhealthy behaviours could achieve that.

Remarkably, stress was quite often mentioned to be a risk factor for cancer, although there is currently no clear scientific evidence for a relation between stress and cancer. More research on how beliefs or perceptions regarding cancer risk factors evolve, could enhance our understanding of people's behaviour in relation to cancer. Additionally, stress was also alluded to as a marker for factors in daily life that indirectly influence cancer risks, such as concerns people face that make exercise or healthy eating difficult or less of a priority.

On early detection and screening, this study shows that the relatively older participants of the Finnish focus group seemed more aware of the importance of screening programs than the younger participants of for instance, one of the focus groups in Czechia. This might be related to the stage of life of the different participants, but perhaps also to the way in which young women are informed in some countries about participation in screening for cervical cancer and the discourse about cancer screening among younger women.

Another relevant finding of this study is that in two focus groups it was mentioned that people, especially men, may not participate in colorectal cancer screening because of invasive testing. This might evoke feelings of shame and fear regarding the invasive part of the screening. This perception which reduces participation of citizens in screening programs for colorectal cancer is well documented.

With respect to early detection of cancer, an important finding of this study, which is supported by several other studies,[10, 11] is that for women with a minority background, it can be very difficult to talk about early signs of breast or colorectal cancer with others, including healthcare professionals. This group is therefore at greater risk for not being diagnosed timely, with potential huge effects of their health.

In addition, access to screening locations in terms of geographical distance can have a large impact on the participation rate of screening programs in some countries. This was discussed in multiple focus groups. Some participants stated that, for some people, reaching screening locations can be difficult and burdensome, particularly for those living in remote areas. Others stated that the distance to the location would mean an overnight stay, which would go together with high costs for some people. Mobile screening locations were mentioned as a solution, which is something that has been or is being explored by the Cancer Mission and in certain countries.[12]

Based on the insights from this study, it is recommended that within EU Member States more and/or clearer information is provided about:

- Cancer not being a death sentence, but a disease that is in many cases curable if diagnosed timely (positive approaches instead of messages of fear);
- Major risk factors and symptoms of cancer and what could be done to avoid exposure to these risk factors (awareness). In addition, it could be helpful to inform people about factors that are perceived as risk factors in the public discourse, such as stress, but for which there is no conclusive evidence;
- How a healthy lifestyle could help to prevent cancer;
- The importance of participation in screening programs and what the actual screening test entails.

In addition, it is recommended to support education on disease prevention in general at a young age by embedding it in school curricula.

4.2. Limitations of this study

The findings of this study showcase perceptions and opinions of citizens in European countries. These findings can shed some light on some common issues that other European countries may encounter. However, it is also important to consider the limitations of this study.

The main limitations of this study are its size and outreach. This study addressed six European countries. The focus groups aimed to have 7 to 15 participants per group, which is not representative of the populations at large. Although some geographic coverage was considered, the findings of these study cannot be generalised to all EU citizens and countries. However, there are lessons from this report that other countries can relate to and learn from. Moreover, previous focus groups organise in other countries by DG RTD and EUHealthSupport when preparing the Cancer Mission, produced similar results. [4]

Another limitation was that six different organisations carried out the focus groups. Therefore, there were differences between the moderation, focus and details of the discussions, despite using the same guidelines as provided by EUHealthSupport.

Likewise, the number of participants in the focus groups differed (range: 3-15 participants). This may have influenced the willingness of some participants to actively participate. It was noticed that some participants were more outspoken and willing to interact and contribute to the discussion than others.

5. Conclusion

Cancer and engagement in cancer screening programs continue to be sensitive subjects in certain regions of the European Union. Information about cancer and screening can evoke anxiety, dissuading individuals from taking proactive steps such as avoiding risk factors or participating in screening initiatives. Similarly, the perception that cancer is an indiscriminate threat, impossible to prevent, can deter people from taking action. Therefore, it is of the utmost importance to enhance the availability, accessibility, and the comprehensibility of information pertaining to cancer, cancer prevention, and early detection across EU Member States. Moreover, in select regions within the EU, concerted efforts are required to overcome barriers associated with geographical distance, which may impede participation in cancer screening programs. Solutions such as mobile screening facilities may prove instrumental in this regard.

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Annex 1. Methods

The EUHealthSupport Consortium was tasked by the European Commission to organise focus groups with citizens in Europe to discuss cancer awareness, prevention, and screening. The focus groups were planned in six European countries: Bulgaria, Czechia, Finland, France, Lithuania, and Malta. The countries were chosen with the intention to have geographic representation across the different European regions and include countries with different backgrounds and challenges on cancer and cancer prevention and screening.

Local public health and academic institutions in each country were contacted to ask for their support to organise the focus groups in their countries. Each organising partner assigned a moderator and co-moderator to facilitate the discussion. They also sourced and hired a suitable venue to host the focus group meeting. The venues had a convenient location for the participants and the moderators. To recruit participants, each organisation searched within their network for participants as well as their own strategies to invite participants. To assist in the organisation of the focus group meetings, the EUHealthSupport Consortium team provided information materials on the Mission on Cancer and on the purpose of the focus group, a guide to assist the moderators in leading the discussions, and an informed consent template.

For each focus group, a moderator and co-moderator coordinated and moderated the discussion with 7 to 15 participants. The participants for these focus groups were 'ordinary' citizens of these countries. The focus groups aimed to have a heterogenous group of citizens of different ages, genders, socio-economic background, living conditions, educational level, etc. The focus groups sought to collect experiences and perspectives of ordinary citizens who have not experienced cancer. Previous experiences have shown that citizens without personal experiences with cancer were also able to draw from experiences and observations from their personal networks [4]. Thus, cancer patients and/or cancer survivors were not considered in these focus groups. However, in two countries, specific focus groups were planned:

In France, only women from 18 to 30 years of age living in Lille were invited to the focus group. The aim of this specific group was to allow the participants to share more specific experiences that women face due to the socioeconomic difficulties in the area where they live in addition to the challenges of healthcare access in Lille. The region of Lille in Hauts-des-France has the highest rates of risk behaviours, such as tobacco and alcohol consumption, and some of the lowest cancer screening rates in France. Due to these circumstances, experts from the Centre Oscar Lambret (our partner organisation responsible for organising the focus group in France) have reported difficulties in reaching people from this area and engaging them in health initiatives, such as PREVENGYN [9]. The difficulties in reaching the population and these young women specifically were reflected in the number of participants recruited for the focus group. Although the Centre Oscar Lambret reached out and invited more than 20 women to participate in this focus group, only 3 women participated.

In Finland, only elderly citizens, age 70 and above, living in the Joensuu, North Karelia were invited to the focus group. The aim of this focus group was to collect experiences and perspectives of elderly citizens in the region of North Karelia because this region has shown positive outcomes due to elderly citizens' participation in other health programmes aiming at reducing risk factors in the region.

The focus groups were planned from April to October 2022. Each country hosted only one focus group, except for Czechia. In Czechia, the organising institution, National Institute of Public Health (SZÚ), was not able to recruit enough participants in one city. Therefore, they opted to have 2 focus groups, one in Prague and one in Brno to recruit the minimum number of participants requested and get a heterogenous group. Each focus group meeting lasted 2.5 to 3 hours; the meetings were in person in a location that was convenient and easily accessible for participants and in the local language with the purpose of creating a

comfortable atmosphere for participants that would allow them to express themselves freely.

A guide was provided to the organising partners in these countries to lead the discussion. For France and Finland, the guide was adapted to address topics that were more appropriate for the specific types of participants of these focus groups. The guide was developed by the EUHealthSupport Consortium team and structured in two main sections: the first section addresses personal behaviour and knowledge about cancer, cancer awareness and prevention, and awareness of risk behaviours; the second section addresses the perceptions and knowledge of citizens on early detection and cancer screening, including access to cancer screening and information on screening and early detection. For each section, the questions led participants from a general topic, such as knowledge of cancer and the topic at hand, to more specific questions about access to information, what actions citizens can take towards preventions and early detection, and what actions can their government and the European Commission can take to improve cancer prevention and screening.

After the focus groups had taken place, each organising institution provided the transcript of the focus group with the personal details of participants anonymised. The EUHealthSupport Consortium team sent the transcripts for translation and conducted the data analysis of the transcripts. For the data analysis, the insights of participants were coded according to the main topics outlined in the guide: cancer awareness and prevention; and early detection and cancer screening. After coding, commonalities and differences of these insights were identified and summarised in the results section of this report (see Annex 2). Furthermore, based on these results, lessons and possible recommendations were drawn on prevention and screening for the implementation of the EU Cancer Mission.

Annex 2. Summary of Findings per Country

Bulgaria

Characteristics of participants

Bulgaria held a focus group with 10 participants. Participants ages ranged between 30 and 52 years of age, and all resided in the city of Sofia. In total, 6 men and 5 women participated in the focus group. The information provided suggests that the group consisted of highly skilled and educated participants. Table 3 below describes the characteristics of the participants in Bulgaria.

Table 3. Characteristics of participants in Bulgaria

Partici-pant Code	Age	Gender	Place of residence	Educational level & Profession
1	33	F	Sofia (city)	Private company owner
2	35	F	Sofia (city)	PhD student
3	46	M	Sofia (city)	PhD, Employee at the Ministry Education
4	32	F	Sofia (city)	Head nurse
5	46	M	Sofia (city)	Marketing
6	46	M	Sofia (city)	Employee at the City Court, owner of private businesses
7	48	F	Sofia (city)	Spanish translator and teacher
8	38	F	Sofia (city)	PhD, Kinesitherapist, physical activity coach
9	52	M	Sofia (city)	Road construction
10	35	M	Sofia (city)	Teacher of music and composer

Cancer awareness and perceptions regarding cancer prevention

The participants in Bulgaria held a strong attitude towards the Bulgarian health system, mentioning that it is performing poorly when it comes to cancer prevention and proactive cancer management. They shared a vision that one needs to rely on oneself when it comes to prevention and early detection of cancer since public health and healthcare fall short in this respect. Participants also mentioned that many people do not have a family physician who knows them well and that they do not trust the public health system. Comments from participants shed some light on inequalities in access to prevention and healthcare, as they talked about wealthy people seeking medical care abroad or in the private sector due to a lack of trust in the public health system and a lack of reliable/accurate information, whereas these were not options for all.

The participants were aware of several risk factors that could increase the chances of getting cancer. They also believed that people are generally informed sufficiently about cancer risk factors, but they do not consider this knowledge when handling risk factors. The risk factors mentioned included: stress, pollution, the exposure to sun, smoking, and eating junk food. They pointed out stress as a risk factor of cancer, but it seemed that they meant that many people have other serious problems in daily life, which seem to have a higher

priority than issues of (un-)healthy lifestyle. For example, one participant pointed out: *"Well of course, the air we breathe is not the best. But the biggest factor is the level of stress. The uncertainty of our everyday lives brings a lot of stress."* Although participants seemed aware of these risk factors, it was not discussed what people themselves could do to avoid them.

Participants in Bulgaria also mentioned that a lack of basic medical knowledge among the population, a lack of information on prevention, and a lack of prevention initiatives have hindered people's involvement in cancer prevention. For instance, one participant mentioned: *"Many people do not use hats. Even the gardeners do not use hats. We have missed these lessons, on how to prevent and how to take care of ourselves from a young age. Since kindergarten kids must learn how to behave. Wear a hat, stay at home or in the shade when the sun is strongest. To be active, to live healthy. All those things which are very simple but the most important."* Another participant mentioned: *"For prevention of breast cancer, there are initiatives, but there are many other cancer diagnoses, which are not mentioned regularly."*

Information about cancer and cancer prevention was also discussed, which shed some light on the stigma on cancer in Bulgaria. Some participants refer to cancer as a deadly disease, often fatal, while some other participants mentioned that they do not want to have any connection with cancer. Participants in Bulgaria referred to 'what they have read' (on the Internet) or 'have heard from others' as their sources of information on cancer. They expressed that there is a strong need for reliable health information from the government and that there is no public health information on these topics in campaigns anymore.

Participants also discussed what would be good ways to inform people about cancer prevention and awareness. Several participants mentioned that health information, including information about cancer and its risk factors, should be taught at schools. But they also emphasised the educative role of parents on what is healthy eating and other risk factors. For example, one participant saw this as a societal responsibility: *"Everyone must do their job. The teacher and the parent must teach the child to act properly, the fundamentals of education, how to eat, etc."*

Perceptions regarding early detection and screening

In general, participants felt that early detection was in their own hands and not much could be expected from their government or from the healthcare sector. It was emphasised that in Bulgaria one should check for symptoms themselves: *"We also must go to more medical tests, despite the fear and lack of faith. We must take matters into our own hands."*

Specifically, regarding screening programs, programmatic screening was not mentioned; some participants mentioned some programmes in the past, but these seemed to be information campaigns rather than screening programmes. One participant mentioned having an opportunistic screening due to a possible family history of cancer and considered it a 'good practice'. Participants had a positive attitude towards participation in screening. Yet, they felt that more campaigns would increase people's participation. Participants expressed that, currently, there is a lack of information about screening, which hinders participation. In addition, it was mentioned that geographical barriers as well as a shortage of professionals hamper access to screening programs in addition to the effects of the COVID-19 pandemic, which has set cancer screening, diagnostics, and treatment on hold.

Likewise, participants discussed on possible options to inform people about cancer screening. Some participants stated that large campaigns could be effective: *"For me the best way is to organise a massive campaign. With publicity, with schools, from the fundamentals to the more complex topics like oncology."* Another participant suggested notifying people to participate in screening programs via text messages that people could receive on their mobile phones.

Czechia

Characteristics of participants

In Czechia two focus groups were held instead of one, due to logistic matters. One focus group was held in Prague and one in Brno, including 6 participants each. Having two focus groups allowed the organisers to reach more participants and have a more heterogenous group. The ages of participants ranged from 17 to 61 years of age. Most reside in urban areas, while only 4 participants reside in rural areas. The total group consisted of 4 males and 8 females. The information provided suggests that there was diversity of educational and professional backgrounds since 4 participants were (high school) students and the other 8 participants were educated and employed citizens. Table 4 below describes the characteristics of the participants in Czechia.

Table 4. Characteristics of participants in Czechia

Partici-pant code	Focus Group	Age	Gender	Place of Residence	Educational Level & Profession
1	Prague	55	F	Rural	Public health worker
2	Prague	61	M	City	Technical worker
3	Prague	31	F	City	Nutritionist specialist
4	Prague	58	F	City	Nurse
5	Prague	28	M	City	Chemist in lab methods
6	Prague	30	F	City	Chemist in lab methods
7	Brno	29	F	Rural	Public health worker
8	Brno	45	M	City	Teacher
9	Brno	17	M	City	Student
10	Brno	18	F	Rural	Student
11	Brno	19	F	City	Student
12	Brno	18	F	Rural	Student

Prague

Cancer awareness and perceptions regarding cancer prevention

The participants of this first focus group in Czechia feel that cancer (prevention) does not receive enough attention, especially given the fact that many people in Czechia are affected by cancer.

It was discussed that it is difficult for people in Czechia to talk about cancer and to face the fact that cancer is part of life. In this context it was also discussed that it is difficult for people that have or had cancer to talk about it, as people do not want others to pity them. People with a history of cancer feel that there is a taboo in society about cancer, according to the participants of the focus group.

The participants think that many people in Czechia are afraid of getting cancer. A cancer diagnosis is by many considered a death sentence according to the participants. According to them, this might be a reason for people to be afraid of a cancer diagnosis and to therefore not visit a healthcare professional. The group discussed how information explaining that

cancer does not need to be fatal, might stimulate people to visit a healthcare professional at an early stage and take more preventive actions.

In addition, it was stated that people might be afraid of doctors, which might prohibit them from visiting a doctor for a check-up.

With respect to risk factors, participants state that smoking is not always recognised as a problem by people in CZ. Furthermore, there was a discussion emphasising that more information on how to prevent skin cancer is needed. People should also check on strange freckles according to the participants. Another type of prevention that is being discussed, is vaccination against cervical cancer. There was some doubt among the participants about the effectiveness of vaccination against cervical cancer. They felt that a virus might change over time and that the vaccination might therefore be no longer effective.

How to inform the public about cancer prevention was extensively discussed. Short videos are considered effective to inform the public as well as information on billboard and/or panels in trams and busses. It was also stated that prevention campaigns should not scare people for cancer, but express that there is hope. Providing information about cancer (prevention) was by some participants considered risky. They thought that informing people might scare them and that too much information might have a negative effect, in the sence that people will get scared and ignore the information.

With respect to what type of information is needed, it was stated that information on where to go to when cancer is suspected is needed. Although out of the scope of main topics of this focus group, it was also discussed that when people have cancer, they should be informed about this in layman's terms by healthcare professionals.

Brno

Cancer awareness and perceptions regarding cancer prevention

The participants of the second focus group in Czechia are overall aware that cancer is common and that it can affect anyone. They recognised that cancer can be associated with risk behaviours but that there might also be a genetic predisposition. They mentioned knowing someone that has had cancer and showed concern that someone close to them could get cancer.

Regarding risk factors that can contribute to the development of cancer, participants mentioned several, including smoking, unhealthy diets, alcohol consumption, not using sunscreen, stress, air pollution, and not using protective equipment at work. Some participants recognised that improving one's lifestyle, stopping unhealthy behaviours (e.g., smoking, drinking alcohol), and persuading others to do so can help reduce the likelihood of getting cancer. One participant mentioned that people should be aware of the need to eat healthy food but that this can be expensive and that it could explain the poor-quality food that people eat which affects their health.

Information about cancer and cancer prevention and how to inform the public about these topics was discussed. The participants acknowledged that although health literacy is poor in the CZ, there is sufficient information about cancer. They mentioned that the information is available, but some people are not interested in it or do not want to learn about it, while other might take the information out of proportion. They also mentioned that some people do not want to talk about cancer. However, they stressed that being informed from an early age can be beneficial to learning how to prevent cancer.

Moreover, regarding the sources of information on cancer and cancer prevention, the participants mentioned several sources of information such as the internet, the media (TV), magazines, promotional leaflets and posters in doctors' waiting rooms, etc., but also from family experiences. However, they stressed that some sources, like the media, can distort the information and thus, all information should be verified by the government (e.g. Ministry of Health) and the public should look into reliable sources. They also stressed that the main

source of information should be doctors and the Ministry of Health. They discussed the main information that is provided to the public should be issued by the Ministry of Health to guarantee its accuracy and trustworthiness. Then, this information can be made available in websites, campaigns, leaflets for doctors'offices, and even through social media. Additionally, the participants (except for one participant) agreed that people should get informed at an early age, where schools should play a role in providing verified and reliable sources of information.

Participants believe that the Ministry of Health and EU policies could do more on cancer prevention. They suggested that more money for campaigns could be allocated. These campaigns could promote preventive measure such as screening and HPV vaccination.

Finally, the participants were asked if they would be interested in being involved in activities promoting cancer prevention. Most participants mentioned that they would not be interested in participating and that people might be ashamed of participating in such activities. Only few participants showed interest to participate in such activities.

Perceptions regarding early detection and screening

The participants discussed the importance of being aware of changes in one's body and that it is one's responsibility to take care one's own health. The participants showed some knowledge on some symptoms that could be checked for cancer, such as moles, blood in stool, lumps in breasts, etc. The mentioned that they feel that they can address and discuss these symptoms with people around them and with their health practitioners.

The participants discussed that they have learned about these symptoms that could indicate cancer from education sources at school and/or in leaflets at the doctors' office. They agreed that there are several sources of information about cancer prevention, early detection and screening, including receiving this information from their doctor, through prevention programmes and campaigns, media (TV commercials focusing on self-examination), the internet, social media, leaflets, etc. They recognised, however, some information on the internet and other media might not be accurate and that should be verified. However, they mentioned that this information should be provided by doctors, at school, or by experts.

Regarding screening programmes, participants showed awareness of the topic. They mentioned knowing about breast, colorectal, prostate, and lung cancer screening. They agreed that cancer screening is important to detect cancer early on. Some participants reported having participated in screening programmes and mentioned that they have discussed the results of the tests with their doctors. They all showed awareness of invitation letters or reminders that citizens receive from their insurance companies to participate in screening programmes. They all agreed that these invitation letters are good to communicate and remind people about the opportunity to participate in screening programmes. They also mentioned that some insurance companies send reminders and provide financial incentives to participate in screening programmes, to which they agreed are good incentives. However, they also stressed that the doctors should provide the information about cancer screening and that they could also remind patients about getting screened. Participants also mentioned that an app sending reminders about health check-ups and screenings could be useful.

The participants also discussed barriers that some people could face that could prevent them from participating in screening programmes. One barrier included fears of what the tests entail and getting a diagnosis confirmed, to which they expressed the importance of early detection through screening that could increase the chances of recovery. They mentioned that sharing successful and positive stories from early detection through screening programmes and sharing information about treatment options could raise awareness on the importance of screening and prevent the fear of getting screened. Additionally, it was also discussed that if people are diagnosed with cancer, they should be informed about this in layman's terms by healthcare professionals.

Another barrier discussed by the participants was the distance to screening centres. They mentioned that these (and other healthcare facilities) are not available everywhere in the country. Particularly for people living in remote areas, the distance to health centres to get screened can prevent participation as traveling can be burdensome.

The participants also agreed that the government and EU policies could do more on cancer screening, such as providing incentives (e.g., offering a day-off to participate in screening programmes) and having national campaigns promoting cancer screening.

Participants were also asked if they would be interested in participating in initiatives and activities promoting cancer screening, to which only a few participants showed interest, while most showed no interest.

Finland

Characteristics of participants

Finland held a focus group with 14 participants. This focus group focused on senior citizens in the region of North Karelia as this region experienced favourable outcomes after the implementation of an initiative to address other non-communicable diseases. The ages of participants ranged from 57 to 91 years of age. Most reside in urban areas, while 4 participants reside in the countryside (rural areas). The participants of the focus group were mostly male (n= 12), with only 2 females participating. The information provided suggests that there was a variety of educational and professional backgrounds, even though all participants reported being retired. Table 5 below described the characteristics of the participants in Finland.

Table 5. Characteristics of participants in Finland

Partici-pant code	Age	Gender	Place of Residence	Educational Level & Profession
1	73	Female	city	retired, auxiliary nurse
2	81	Male	city	retired, truck driver
3	80	Male	city	retired, postal worker
4	67	Male	city	retired, bakery entrepreneur
5	73	Male	city	retired, printing industry
6	68	Male	countryside	retired, radio and telecommunications installer
7	67	Male	city	retired, truck driver
8	91	Male	city	retired, farmer
9	65	Male	city	retired, informal caregiver
10	57	Male	countryside	retired, prison worker
11	74	Male	city	retired, construction industry
12	79	Male	city	retired, driving planner
13	78	Male	countryside	retired, metal industry
14	69	Female	countryside	retired, auxiliary nurse

Cancer awareness and perceptions regarding cancer prevention

The participants in Finland discussed and acknowledged how common getting cancer can be. Most expressed having someone from their network or knowing someone that has experienced cancer. They mentioned that in previous years cancer was a ‘taboo’ topic, it was not openly discussed, and it also meant a ‘death sentence’. One participant shared the experience of a parent having cancer and having unfavourable outcomes due to the lack of awareness and information. However, they recognised that in more recent years, the topic is not a ‘taboo’ subject anymore and that it is more openly discussed within their network. They recognised that the fear of getting cancer is present but when the topic is openly discussed, it could help people who have (had) cancer. They mentioned that discussion groups (such as this one) can help in raising awareness and opening the discussion on this topic.

The participants discussed the sources of information where they have gotten informed about cancer. Some mentioned checking information online and discussing this information with a health professional. Some indicated that for them the best source of information is a doctor and other healthcare professionals. They shared the experiences that in previous years there was insufficient information about harmful substances (e.g., asbestos) or habits (sun exposure), and that there is more awareness and information available about substances that can be harmful to one’s health and that could cause cancer.

The participants showed some awareness about the importance of keeping a good/healthy lifestyle and its benefits on one’s own health. However, some mentioned that despite this awareness, they have not changed their habits to some more beneficial habits (e.g., having a healthier diet and exercising). Some mentioned that despite having a healthy lifestyle one can still develop cancer due to a hereditary predisposition. They also pointed out the effects of stress on lifestyle and being an important contributing factor that could trigger cancer.

During the discussion, a couple of contributing factors towards developing cancer were discussed, mainly sun exposure and tobacco and alcohol use. Regarding sun exposure, the participants mentioned being more aware of the possible harm that sun exposure can cause than they were when they were young(er). Some described keeping themselves under the shade and wearing long sleeves and clothes to avoid sun exposure. They also noticed that younger generations are more aware of the importance of avoiding sun exposure. Regarding tobacco and alcohol use, they discussed some policies in place to reduce their use, such as taxation and labelling. They agreed that this type of measures may not have an influence on (heavy) users, who will consume these products despite the price or graphic "warning pictures"; however, these may influence the reduction in the use of alcohol in younger generations, as would education. Some pointed out that taxing these products may not have a desired outcome, suggesting that users would find a way of getting these products elsewhere and that it could introduce a black market and the production and circulation of uncontrolled (homemade) goods.

Perceptions regarding early detection and screening

The participants seemed aware of the importance of early detection as they mentioned the importance of checking one's body regularly to notice any changes (e.g., appearance of moles or changes in colour and size of moles, self-exploration of breasts) and communicate any irregularities or changes to their doctors.

The participants were aware of the existence of the cancer screening programmes in Finland and of their importance to detect cancer early. They mentioned that these screening tests can bring a sense of security that nothing can go unnoticed (and get treatment early) and that they are able to discuss this and that they recommend to their peers to get screened. They have noticed the frequency of the screening tests and when these stopped for them (one participant mentioned that it was at the age of 70). They discussed that they did not understand the age limits of the screening programmes (only one participant mentioned that they understood and agreed on having age limits in the screening programmes). During the discussion, breast and cervical cancer were mostly discussed in terms of the age groups that they target; however, the discussion also considered colorectal cancer, where most participants mentioned that they think that screening programmes should be extended to anybody or that the age limits should be broader (start at an earlier age and end at a later age).

Some participants shared their experiences in participating in the screening programmes and regarded them as positive. They mentioned receiving good service and that they were informed about the results and followed up if needed. However, some mentioned that, in some cases, practitioners did not discuss the test results with them but rather directed them to 'Omakanta' (the digital public health service portal). The participants recognised and stressed the importance of communicating any changes to one's doctor and the importance of doctors in communicating the results of the screening tests to the patients.

The participants discussed possible reasons for the low participation in screening programmes. One participant mentioned that there can be an element of shame in mentioning changes or irregularities to their doctors and in attending the screenings (e.g., gynaecological testing). However, this participant mentioned having no shame on discussing with their practitioner about aspects concerning their health, as they believe that otherwise it could be too late to address health concerns and that issues could become severe. One participant mentioned that having public figures (e.g., celebrities) speaking about health issues and testing has reduced the shame surrounding these topics and has helped in raising awareness in the importance of getting checked and tested.

The participants discussed and mentioned some barriers that people can face to get screened in Finland. They mainly focused on the distance to centres where screenings take place, as it can be difficult to reach for people living in remote areas, due to bad weather conditions. The actual distance, transportation, and transportation costs to reach the

facilities, especially with health services decreasing in areas where the population is also shrinking. One participant mentioned that some remote areas have experienced a population loss due to migration (to cities), which has caused a certain neglect to these areas in terms of access to services and political attention. However, a participant mentioned that screening access could be improved if the screening centres could be 'on wheels' (like an ambulant laboratory), expanding the services that occupational health practitioners give, or expanding the training program of doctors to include screening so that general practitioners and nurses can conduct the screening. The participants also mentioned that more funding is needed to expand screening programmes and improve their accessibility.

France

Characteristics of participants

France held a focus group with 3 participants. This focus group focused on young female citizens living in deprived areas in Lille. All of them reported living in Roubaix, Lille. Originally, the organising institution (the Oscar Lambret Centre) was able to contact more than 20 women to invite them to participate in the focus group. However, they reported that the low participation is a reflection of the difficulties to engage with people and mobilising them into participating in similar activities and even in prevention programmes (e.g. PREVENGYN [9]) due to socio-economic and cultural disparities. The participants were 25 and 26 years of age. The information provided suggests that there was a variety of educational and professional backgrounds. One participant had little knowledge of French; she reported having worked in sales before but currently being a stay-at-home mother. One participant reported being a PhD student, and the other reported working as a health assistant and participating as an animator in camps for children and adolescents while currently going on retraining for a new profession. Table 6 below describes the characteristics of the participants in France.

Table 6. Characteristics of participants in France

Partici-pant code	Age	Gender	Place of Residence	Educational level / Profession
1	26	Female	Roubaix	Retraining Health assistant Animator at camps
2	25	Female	Roubaix	Former sales worker; stay-at-home mother
3	25	Female	Roubaix	PhD student

Cancer awareness and perceptions regarding cancer prevention

During the focus group discussion, the participants were asked if they are informed about cancer. The participants shared that they do not feel well informed about cancer, even though they showed an interest in learning more about it. One participant told of having a family history of cancer, which has helped her to be aware and to seek being better informed about it. Another participant shared that she is interested in the subject as it is important. However, they also expressed that they feel anxious and scared when they get information about cancer, especially when the emphasis is on the high percentage of women affected

and that the information can feel negative and provoke feelings of stress and anxiety. They recognise that, at the same time, these figures make women realise that they should act. For example, recognising that the high number of cancers and low numbers of people screened that are shared can deter and encourage people to get screened. They reported that they have gotten this information from social media (e.g., news from Twitter), TV, and other resources on the internet (e.g. Doctissimo portal was mentioned). However, they mentioned that cancer is not something that is commonly discussed with their general practitioners. They commented that they only attend doctor consultations when they need to treat a health issue, but that they are not being informed on cancer (and other health related issues) during consultations. One participant mentioned that she got information regarding gynaecological prevention from her midwife. It was suggested that other health professionals, such as pharmacists, could also provide health information to citizens (like information on cancer and cancer prevention), given the overload that practitioners/doctors experience.

Moreover, it was agreed that the information they have gotten on cancer is not sufficient and that they would like to be better informed. One participant stressed the importance of being well informed and shared that these topics are, in fact, discussed within her family and peers. However, another participant shared that the topic is not discussed with her family and that some aspects of cancer, particularly those related to sexuality (e.g., breast and cervical cancer), can still be a taboo topic and, thus, difficult to discuss. The participants agreed on the importance of having more spread-out information and campaigns on cancer prevention and not only during raise-awareness months (e.g., Pink October and Blue March). One participant stressed that information needs to be provided from a young age at school, continued through adulthood, and that now social media can be used as a tool for this purpose.

Some risk factors were discussed during the meeting, such as lack of physical activity, smoking, alcohol consumption, and unhealthy diets. Although physical activity was not widely discussed, participants shared that they don't participate in any physical activity (e.g., exercising) despite being aware of its importance on health. One of the participants said she did not exercise because there was no one to take care of her child in the meantime. The moderator reassured them that moving and having some kind of physical activity is already good even if they do not take part in sports. Likewise, participants mentioned being aware of having a healthy diet and that there are already a lot of campaigns with this message, but which should convey more simple messages to younger audiences. They did not go into detail about their diet habits.

Regarding smoking, participants mentioned being aware that smoking is detrimental to one's health; however, one participant shared being a smoker despite having family members who were affected by cancer due to smoking. Since most of her family members were smokers, she feels that, despite knowing the negative effects of smoking, it was seen as normal and that influenced her smoking habits. She mentioned that she has seen a difference on the perceptions of smoking, particularly around non-smokers and specially children (e.g., adults are more careful not to smoke around children). She believes that preventing smoking should start at a family level so that children do not become smokers. In her experience, talking about smoking and its consequences with younger people has been helpful in raising awareness. The participants also discussed on the importance of providing thorough support to people that seek to quit smoking and to not stigmatise these people that are trying to quit.

Furthermore, regarding the consumption of alcohol, the participants mentioned that they are also aware that alcohol can be harmful to one's health. However, they pointed out that drinking alcohol is part of the French culture, and that drinking alcohol (and alcoholism) has been trivialised, thus diminishing its real effect and impact on health. They mentioned that in practice there is no real control on alcohol consumption for young people. A participant suggested that, like with tobacco products, there could be spaces dedicated only to selling

alcohol, which could work to reduce alcohol consumption or, on the contrary, could become a profitable business and have the opposite effect.

In the discussion, HPV vaccination was also addressed. Participants seemed to know about its existence but not in depth. One participant mentioned that she learned about it, but when she asked her doctor about it. The practitioner/gynaecologist mentioned that it was only for teenagers and that for her it was too late, with no further explanation leaving her ill-informed. She learned that she could get vaccinated but that it would not be covered by the system and thus it would cost her. However, she still feels it would be good for her to get vaccinated.

Perceptions regarding early detection and screening

Early detection through body exploration was discussed with the participants. In this discussion, the participants seemed aware of the importance of checking one's body for any changes (mainly breast palpation was mentioned). Some participant mentioned that this topic is openly discussed with her family and that her midwife taught her how to do it and to do it regularly; but another participant mentioned that she remains uncertain how to detect an abnormality. Another participant mentioned that she checked her breasts only when she is in pain. The experiences of some of these women suggested that, although they have been taught on auto palpation, questions remain and that they didn't feel well informed overall.

Regarding participating in screening, one participant mentioned that she actively participates in screening tests and that she is aware of their existence and importance. Only one of the participants mentioned that she has heard of these screenings and the screening invitations that people get, while the others mentioned not knowing about them. She mentioned that the awareness has been raised within her family due to cancer history. However, one of the other participants showed no knowledge or awareness of the existence of screening tests, such as pap smears (what they were, what they were for), and had had never participated in one before. The third participant had not heard of pap smears until recently, when the gynaecologist told her about it and did a pap smear during a gynaecological examination. The participants agreed that having open discussions about these tests and discussions about cancers do raise awareness and do inform women on these issues. They agreed that these discussions can motivate them to speak about it with their doctor or midwife and to participate in screening tests. However, the shared perception regarding the results of tests (e.g., pap smear) was that practitioners do not explain what the tests are for, how are they conducted, what happens with the results, and the actual results. They felt that the practitioners do not provide enough information on self-examination and screening tests.

During the focus group meeting, the topic about information on screening and cancer was raised, such as campaigns like Pink October and Blue March. The participants mentioned that the colours associated to these campaigns can cause gender related connotations (e.g. pink for girls, blue for boys), which could cause misconceptions on to whom is the campaign targeting, since the participants mentioned that 'Blue March', which is related to colorectal cancer, was only directed to men when in fact is to both men and women. One participant reiterated that information about cancer and cancer screening should be delivered from an early age such as in adolescence to promote awareness on these issues and for people to realise where and with whom to seek help if needed. She also mentioned that providing information on cancer at an early age can help to reduce the 'taboo' and shame factor that could accompany cancer (e.g., like breast and cervical cancer) and help open the discussion with the family and peers. The participants also agreed that this information could be provided in schools to promote discussions with peers, at home, and with partners.

Regarding the source(s) of information about cancer and cancer screening, the participants mentioned that this information should come from doctors and health practitioners (e.g., midwives). They mentioned that doctors could speak to young people and parents (so that they can also talk about it with their children) in a way that reduces any type of

embarrassment and to inform which doctor to attend when and if needed. The participants mentioned again that social media and influencers could be used to spread information about cancer awareness and screening. One participant mentioned that with influencers, young people feel more connected to the message and the person giving the message. If campaigns were appropriately delivered through these mediums (influencers in social media), these could cause a bigger impact. Institutions, parents, and other authorities could direct people to such influencers and social media accounts for getting (adequate) information. They mentioned that there is a lack of information on how and when to get screened, and that information should be more widely spread so that people participate in these screenings to prevent and early detect cancer.

Lithuania

Characteristics of participants

Lithuania held a focus group with 10 participants. Participants' age ranged from 18 to 65 years of age. All participants resided in the city of Kaunas, except for two participants that lived in a village in Kaunas district. Seven women and three men participated in the focus group. The educational and professional background of participants was rather heterogenous. Table 7 below describes the characteristic of the participants of the focus group discussion in Lithuania.

Table 7. Characteristics of participants in Lithuania

Partici-pant code	Age	Gender	Place of Residence	Educational level / Profession
1	65	female	Kaunas	higher university
2	23	male	Kaunas district/village	student
3	18	male	Kaunas	high school student
4	18	female	Kaunas	high school student
5	35	female	Kaunas	chief administrator
6	44	female	Kaunas	higher university
7	30	female	Kaunas	personal trainer
8	21	male	Kaunas	student
9	51	female	Kaunas	Vocational education
10	55	female	Kaunas district/village	college

Cancer awareness and perceptions regarding cancer prevention

The focus group included a mixture of older and younger participants. A younger participant mentioned that nowadays people talk more freely about cancer. Yet on the other hand, other participants said that it can be very difficult for people to talk about cancer, especially with persons who have (had) cancer.

With respect to perceptions of participants regarding cancer prevention and risk factors, it was stated that even though as an individual you try your best to have a healthy lifestyle, environmental factors make it difficult to prevent cancer. It was mentioned that unhealthy environmental factors that could cause cancer, are actual created by people. In that sense, personal behaviour is the most important determinant of cancer by some.

There is awareness among participants that unhealthy (processed) food, smoking, excessive alcohol consumption and stress are risk factors for cancer as well as having specific genes that increase the change of getting cancer. Physical activity is seen as a preventive measure. At the same time there is a general conception that it is difficult to prevent cancer. Some participants state that regular check-ups are the only thing that could help prevent cancer.

In addition, there seemed to be agreement that education on cancer prevention should start at an early age. Prevention of cancer should be part of the school curriculum. It was also mentioned that trips with school children to exhibitions on the human body could contribute to prevention.

Perceptions regarding early detection and screening

When it comes to the recognition of early signs of cancer, it was stated that a lump in your breast, weakness, fatigue, weight loss and bleeding could be early signs of cancer. Yet other participants stated that these could also be symptoms of something else.

With respect to screening, several participants stated that they had participated in a screening program. Participants considered screening programs to be important. Some mentioned that for young people more persuasive communication might be needed for them to participate in a screening program.

Access to screening programs is limited for some people because of long distances to screening locations and in some cases unavailability of (public) transport. Participants have ideas on solutions to overcome geographical barriers for screening, which is seen as a major barrier, such as offering screening on location on a particular day.

Furthermore, men are more difficult to involve in screening programs than women, because men may be afraid of and avoid invasive tests. It is therefore considered important to provide clear information about the screening program and explicitly mention that some tests are not invasive.

A younger participant stated that she got invited for screening only via her family doctor. She and other participants thought that an email reminder for screening programs would increase the participation rate in screening programs among younger persons.

The topic on information about cancer and cancer prevention was also discussed in more general terms. Participants stated that information on the internet is not always trusted by people and therefore people might prefer to receive information about cancer and cancer prevention via their family doctor. It was suggested that a lifestyle manager could take over the task of the family doctor to inform people about cancer prevention, but not all participants agreed on this. Some would prefer to receive information from their family doctor instead of a lifestyle manager.

It was also mentioned that visual information is important to inform people, similar to the images on cigarette packages and that information about prevention on TV would be appreciated. Famous people talking about cancer prevention was thought to be a good way to inform people.

Malta

Characteristics of participants

Nine citizens from various localities in Malta participated in the focus group discussion. Six participants identified as female and three as male. Participants ranged in age from 31 to 78. The participants live in different villages, towns, and cities across the island. The professional background of participants was mixed. Table 8 below describes the characteristic of the participants of the foucs group discussion in Malta.

Table 9 Characteristics of participants in Malta. *Fictitious names were used instead of codes to blind the participants' real names and information.

Partici-pant code*	Age	Gender	Place of Residence	Educational level / Profession
Connie	32	Female	Malta	Secretary
Sandra	72	Female	Malta	Retired teacher
Stella	76	Female	Malta	Retired
Miriam	76	Female	Malta	Housewife
Romina	67	Female	Malta	Housewife
Frankie	68	Male	Malta	Retired
Joseph	46	Male	Malta	Librarian
Manwel	31	Male	Malta	Teacher
Carmen	31	Female	Malta	Bank employee

Cancer awareness and perceptions regarding cancer prevention

A green environment with many trees was thought as something that would help prevent against cancer, because it provides fresh air and shade, so people are not exposed directly to the sun. Exercise, healthy eating (with fruit and vegetables), not smoking or being exposed to smoke, not being exposed to toxic fumes were all mentioned as elements of "living well" that prevent cancer.

Participants believed food could pose a risk for cancer, either the food itself such as when eating meat from cows, chicken, or rabbits, which was mentioned by one participant. Although at the same time, two other participants mentioned they were not aware that intake of red meat can cause cancer. Three participants mentioned the risk of contaminated food, such as with produce that had been sprayed with pesticides which can cause cancer. Two participants also made note of the chemicals in plastic bottles and the possible release of those when exposed to the sun.

Seven out of nine participants were not aware that alcohol can cause cancer before coming to the discussion. On the question of alcohol labelling, participants thought some warning label was a good idea, but they also raised doubts whether consumers would even look at it.

Participants mentioned that there is a lack of awareness but also indifference about cancer amongst the Maltese citizens. Several/ participants believed many Maltese people do not take cancer risks and prevention that seriously. They said that while quite some adults take protective measures such as using sunscreen and wearing hats against sun exposure,

many also do nothing. There is more concern for protecting children, however, as “in Maltese culture we are very concerned about our children and make it a point that they wear sunscreen and hats.” They also believed that because of their children, women are more cautious and better informed about the prevention of cancer.

Perceptions regarding early detection and screening

Most participants said they did not talk about cancer, prevention, risks or screening with their families or friends. Two participants mentioned that they believed the Maltese “acted” more than they talked about it. One participant however did discuss screening with family and friends.

There seemed to be consensus that the government was doing very little in terms of information (campaigns) on prevention, screening and early detection. Four participants also felt cancer and its prevention needs to be discussed more in the media. Participants felt there was little information distributed by the government, Ministry of Health, or in the media. They agreed that awareness raising was key to make Maltese citizens more aware and concerned of the risks and taking preventive steps to protect themselves. This could be in the form of an information campaign by the Ministry of Health with TV and radio advertisement, posters and leaflets, and posting on social media. They mentioned education, including in schools, as key to help emphasising the risks. Participants concurred that if citizens are more educated on the subject, there is a good chance that one could avoid cancer.

All participants said they were aware of the different types of screening offered to avoid or detect cancer at an early stage. They said screening was good, but people might not always attend because of the “Maltese culture” or because they are afraid of the result or fear being hurt. One participant mentioned the Ministry of Health could do more about screening but did not go into the specifics on how.

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To support the Cancer Mission, a series of focus groups were organised with citizens in six EU Member States: Bulgaria, Czechia, Finland, France, Lithuania, and Malta. Focus groups addressed cancer awareness, prevention, early detection, and screening. This study underlined the importance of improving information and communication on cancer prevention and early detection and screening for EU citizens. More and better actions are needed to address barriers and support citizens in preventing cancer.

Studies and reports

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