



D2.2 -

# Paper on countries' stakeholder profiles for CPP

February 2025





Project number: 101104432

Project name: Personalized CANcer Primary Prevention research through Citizen

Participation and digitally enabled social innovation

Project acronym: 4P-CAN

Call: HORIZON-MISS-2022-CANCER-01-01

Version number	
Status	Second draft
Dissemination level	
Due date of deliverable	20/02/2025
Actual submission date	18/02/2025
Project officer	Marianne da Silva
Work package	WP2 - Paper on countries' stakeholder profiles for CPP
Lead partner	INSA/UA
Partner(s) contributing	ENSP, INOMED, WP2 partners
Authors	
Main author name	Luis Filipe Roxo
Contributing authors	Ana João Santos
	Charis Girvalaki
	Marius Geantă
	4P-CAN WP2 study team
	Mafalda Sousa-Uva
Reviewers	
Reviewer name	ENSP

**Statement of originality** This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.





# **Version Tracker**

Date	Version	Author	Description
31/10/2024	0.1	Luis Filipe Roxo First Draft	
			Second Draft
20/02/2025	20/02/2025 0.2 Luis Filipe Roxo		(Update Executive summary,
20/02/2023	0.2	Luis Filipe Noxo	Characteristics of stakeholders,
			Results and Discussion)



# **Table of Contents**

List of Figures	8
List of Tables	9
List of Abbreviations	10
Executive Summary	11
Deliverable Introduction	12
Deliverable objective and scope	12
Relation to other WPs and deliverables	13
Content of the deliverable	13
Background	15
Methods	17
Framework	17
Data sources, data collection methods and analysis	18
Quantitative data	18
Qualitative data	19
Results	21
Survey results	21
Interviews results	22
Public sector	24
Academia/Research	26
Private sector	29
Media	31
Civil society	33
Iron Curtain of Cancer Cases	36
Discussion and conclusions	36
Characterization of CPP stakeholders	37
Iron Curtain of Cancer Cases	
Merits and limitations	
Conclusions	



References	40
List of Sunnlementary Materials	42



# **List of Figures**

**Figure 1**: Results from the survey to CPP stakeholders. Percentage of participants identifying each of the five sectors (public sector, academia/research, private sector, media, and civil society) as having the main role in change, being the most proactive, and the most influential, shown for the total sample, and for respondents from Western and Eastern countries (%).

Figure 2: Countries of participants in the interviews.

**Figure 3**: Themes and overarching concepts identified in the qualitative analysis for the five sectors (public sector, academia/research, private sector, media, and civil society)



## **List of Tables**

**Table 1**: Description of penta-helix sectors.

**Table 2**: Characterization of participants of the survey: Number of participants by country and country group.

**Table 3**: Characterization of participants of the interviews: Number of participants of the interviews by sector, country and country group.

**Table 4**: Overview of activities, motivations, barriers and opportunities, among public sector (A1 – A3).

**Table 5**: Overview of activities, motivations, barriers and opportunities, among academia/research (B1 - B4).

**Table 6**: Overview of activities, motivations, barriers and opportunities, among private sector (C1 – C3).

**Table 7**: Overview of activities, motivations, barriers and opportunities, among media (D1 – D3).

**Table 8**: Overview of activities, motivations, barriers and opportunities, among civil society (E1 – E3).



## **List of Abbreviations**

- CEE Central and Eastern Europe
- CPP Cancer Primary Prevention
- D Deliverable
- EU European Union
- WP(s) Work Package(s)



## **Executive Summary**

Over the last decades, cancer incidence has been increasing in Europe, being cancer one the leading causes of death. Meaningful differences persist in cancer incidence and mortality between Western and Eastern European countries, highlighting regional differences regarding risk factors (e.g., smoking habits). Cancer Primary Prevention (CPP) aims to tackle these modifiable factors and to decrease individual risk of cancer. Yet, implementing CPP goes beyond the actions of the governments, and involves a complexity of actions from different stakeholders in society.

In this study, we use mixed methods to characterize CPP stakeholders of public sector, academia/research, private sector, media and civil society. We also aim to get a deeper understanding on the regional differences in cancer incidence and mortality. Descriptive statistics were performed to analyze survey results - relative frequencies (%) were computed for each variable, and are presented for the total sample and stratified by country group (Western and Eastern). Data from interviews were analyzed by thematic analysis.

Results from a survey to 110 CPP stakeholders show that public sector is considered the main driver of change, the most proactive and influential sector in both Western and Eastern Europe. Yet, Eastern countries place greater emphasis on the role of other sectors in CPP, highlighting possible inadequacies of the public sector.

Moreover, we conducted 33 interviews to stakeholders from nine countries and, for each sector, we identified different themes (ideas overlapping activities, motivations, barriers and opportunities, aiming to characterize the actual and potential role of each sector):

#### Public sector

- "Looking after citizen's health", characterizing the responsibility over the health of
  individuals, and the power to define strategies and to allocate resources;
- "Making the system work", describing the role of providing structure to different activities;
- "Providing care", reporting the involvement of public sector in operational activities close to the public.

#### Academia/Research

- "Scientific credibility", characterizing the role of building trustworthy knowledge;
- "Diversity of approaches", describing a great variety of disciplines and research areas;
- "Getting out of the lab", highlighting the potential of academia/research having a role closer to society;
- "Life in academia/research", describing constraints and motivations that are very specific to the way academia/research operates.



#### Private sector

- "Profit-oriented", characterizing how financial benefit can drive the involvement of private sector in CPP;
- "Resources and operational activities", showing how private sector can support other sectors and develop their own activities;
- "Ethics and responsibility", stressing the relevance of responsible practices that protect the individuals.

#### Media

- "Capacity to reach people", highlighting the potential of media's presence in everyday life;
- "Diversity and scope", describing a great variety of media channels that can reach people from different social sociodemographic groups;
- "Information and dissemination", emphasizing the role of providing information, its utility and the relevance of its quality.

#### Civil society

- "Proximity to people", describing a closer connection to individuals and the community, and the use of less formal approaches;
- "Advocacy and voice", describing how civil society can be agents to communicate needs and to drive change;
- "Do what others don't do", highlighting the role of civil society identifying and filling gaps from the other sectors.

Some barriers and opportunities from Eastern countries may potentially be tackled to reduce regional disparities, such as limited government interest, lack of strategy, constraints due to small size of the countries, and the importance of international cooperation.

This study provides evidence on how CPP goes beyond the actions of the public sector and how, to unravel the full potential of CPP, an appropriate interaction and complementary between stakeholders from different sectors is desired.

## **Deliverable Introduction**

#### Deliverable objective and scope

 In order to unravel the full potential of CPP reducing cancer incidence and mortality, and addressing disparities in cancer incidence between countries, the engagement of different sectors of society may be required. Understanding the actual and potential role of different stakeholders in CPP is the first step in planning their engagement.



- We aim to characterize stakeholders from the public sector, academia/research, private sector, media and civil society (the five sectors of the penta-helix approach), using both quantitative and qualitative data.
- Moreover, we aim to shed new light into the *Iron Curtain of Cancer Cases* (West-East divide in cancer incidence and mortality). We categorize countries of the consortium into Western and Eastern Europe and compared them regarding CPP stakeholders roles, activities, opportunities and barriers at national level.
- This document presents an overview of the scientific paper that has been submitted to a scientific journal. The publication of this paper will allow the dissemination of these findings among the scientific community, policymakers and other stakeholders of countries within and outside the project consortium.

#### Relation to other WPs and deliverables

The present deliverable is part of Task T2.1 ("CPP performance indicators and stakeholders mapping in 4P-CAN Countries"), using the penta-helix framework that allows the characterization of both traditional and non-traditional stakeholders. Data from this deliverable will be used in WP5 ("Living-Labs for primary prevention of cancer"), to inform the creation of CPP-related Living-Labs, in Romania and Bulgaria. Moreover, information about the activities, barriers and opportunities of each sector will be used in WP6 ("Multistakeholders' co-creation of CPP policy recommendations"), to inform national and supranational recommendations for the uptake of CPP and the reduction of inequalities (e.g., informing the potential role of civil society, in countries with less developed CPP programs). Finally, the findings of this study will be disseminated (WP7, "Dissemination, Evaluation, Education, Communication") among the scientific community, and will be used to support stakeholder engagement.

#### **Content of the deliverable**

This document presents an overview of the scientific paper that has been submitted to a scientific journal. Therefore, it follows a usual structure of scientific papers:

- Background, presenting the main evidence that justifies the study;
- Methods, describing the procedures used in data collection and analysis;
- Results, presenting the descriptive analysis of quantitative data and the thematic analysis
  of qualitative data;



- Discussion and conclusions, summarizing the main messages of the study, its merits, limitations and implications;
- References, presenting previous literature that supports the study; and
- Supplementary Material, presenting additional material used in the study that may be helpful for its interpretation.



# **Background**

Over the past decades, Europe has experienced an upward trend in the incidence of cancer across all sites, although this growth has moderated in recent years (Arnold et al., 2015; Ferlay, Colombet, Bray, 2018; IARC, 2024; American Cancer Society, 2024). On the other hand, overall cancer death rates are steadily decreasing in Europe (Ferlay *at al.*, 2018). A significant disparity exists between regions, with countries from Central and Eastern Europe (CEE) having higher cancer mortality and incidence rates than Western ones (Santucci *et al.*, 2022; Ferlay *et al.*, 2024). We will use the designation "*Iron Curtain of Cancer Cases*" to address this West-East divide in cancer cases and mortality.

Lung cancer is the most diagnosed cancer among males in countries such as Montenegro, North Macedonia, and Ukraine, whereas prostate cancer predominates in most Western European countries. Among women, the incidence of cervix cancer in Bulgaria, Moldova, and Romania is more than twice as high as in Italy or Portugal (Ferlay *at al.*, 2018).

The *Iron Curtain of Cancer Cases* highlights differences in lifestyle, behavioral patterns and exposure to risk factors. CPP may perform a pivotal role tackling these differences. Cancer prevention can be considered in three different levels (primary, secondary, and tertiary) and has the potential to substantially reduce mortality and morbidity, being an effective long-term cancer control strategy (Wild *et al.*, 2020). CPP is considered to be the most impactful one in outcomes as it blocks the onset of cancer by changing exposure to risk factors (such as alcohol, radiation, tobacco smoke, overweight and obesity, occupational carcinogens, between others), effectively contributing to the decrease of cancer incidence (Schüz *et al.*, 2015; Vineis & Wild, 2014). Current CPP measures aim to promote the adoption of behaviors that reduce the risk of cancer, and to discourage the exposure to carcinogenic agents (Wild *et al.*, 2020). This requires a multifaceted role from several stakeholders who may contribute to policy development, resource allocation, community engagement, research, innovation, advocacy and education efforts, among others (Schüz, Espina & Wild, 2019).

Considering the potential of CCP in reducing the number of cancer cases and deaths, most countries have approached CCP through the development and implementation of National Cancer Control Programmes (WHO, 2002). These are public health programmes aiming to implement systematic, equitable and evidence-based strategies for cancer prevention, early detection, diagnosis, treatment, and palliation, which focus issues such as tobacco and alcohol use, physical activity and vaccination (WHO, 2002). While the effect of national preventive policies on cancer incidence and mortality has not been extensively studied, it is believed that they have not been able to develop the full potential of CPP.

CPP must be a collective undertaking, as individual behaviors are deeply intricated in social, cultural, political and environmental structures (Schüz, Espina & Wild, 2019) and some preventive measures require action at a populational level (Espina et al, 2013). Active



engagement from other sectors of society, such as media, private sector, and civil society, may be required (Akselrod et al, 2024). Understanding the actual and potential role of these stakeholders is the first step in planning their engagement.

In this study, we aim to characterize the role of CPP stakeholders from different sectors across Europe, identifying their activities, motivations, challenges and opportunities in their actions, and to shed new light into the *Iron Curtain of Cancer Cases*.



## **Methods**

This study is part of the 4P-CAN Project "Personalised cancer primary prevention research through citizen participation and digitally enabled social innovation" funded by the Horizonte Europe program (2021-2027, cluster MISS-CANCER-01), developed by a consortium from 11 European countries (4P-CAN, 2024). This project uses multidisciplinary resources and methods to understand determinants to policy implementation and adherence to healthy lifestyles, with the main goal of improving CPP and reducing inequalities in countries from Eastern Europe. The Portuguese project team involved in 4P-CAN project was responsible for leading the task of stakeholder's characterization.

#### **Framework**

To characterize the stakeholders, we used the penta-helix approach, a framework commonly used to understand the roles played by various sectors driving innovations (Sudiana *et al.*, 2020). The penta-helix was considered a suitable approach, given the aim of 4P-CAN Project of creating innovative approaches to CPP. Thus, stakeholders were grouped into five sectors: public governance/public sector (hereafter "public sector"), academia/research, private sector, media, and citizens/civil society (hereafter "civil society"). Table 1 presents a characterization of these sectors. This information was presented to all participants.

Sectors	Description
PUBLIC SECTOR	All state institutions and organizations responsible for public administration and the implementation and management of government policies and programs.  Government and ministries, public health institutes and technical and scientific directorates (e.g., health directorate), etc.
ACADEMIA/ RESEARCH	Institutions involved in knowledge transfer to population and society; institutions that promote or carry out research in cancer field and strive to stimulate discoveries that benefit people, and to promote new standards of knowledge.  Universities, research institutes, foundations and scientific, expertise associations, etc.
PRIVATE SECTOR	Sector of a national economy under private ownership in which the allocation of productive resources is controlled by market forces, rather than public authorities and other sectors of the economy not under the public sector or government.  Industries and any other profit-oriented organization; pharmaceutical industries, etc.
MEDIA	Media-based private or public institutions and organizations, and individuals that contribute to the "capital of information" within a particular social context.  Television, internet, newspapers, journalists, bloggers, influencers, and youtubers, etc.
CIVIL SOCIETY	All institutions or organizations that are public non-profit culture-based public.



Non-profit non-governmental organizations (e.g., Cancer Leagues), patients, or hospitals associations, volunteering, etc.

Table 1: Description of penta-helix sectors

To shed new light into the determinants of the *Iron Curtain of Cancer Cases*, consortium countries were divided in two groups: Western (Belgium, Ireland, Italy, and Portugal) and Eastern (Bulgaria, Montenegro, North Macedonia, Romania, and Ukraine).

#### Data sources, data collection methods and analysis

We used a mixed method approach encompassing a cross-sectional study, with data from an online survey to CPP stakeholders, and qualitative data obtained through interviews to CPP stakeholders.

#### Quantitative data

A questionnaire was distributed to stakeholders from the participating 4P-CAN consortium countries, aiming to characterize CPP stakeholders and the roles of various sectors within the penta-helix model.

Survey data were collected using a snowball method of sampling. The 4P-CAN consortium partners were contacted by the Portuguese research team and asked to identify at least six national CPP stakeholders and to send them an invitation to participate in the survey. The recruitment process involved distributing an invitation email containing the survey link, and an informative brochure (including a brief description of the 4P-CAN project, the purpose of the survey, the recruitment of participants, data analysis and dissemination, and the research team contacts for further information). Invitations were sent by the consortium partners on the same date in January 2024, to their list of CPP stakeholders. The decision to ask partners of each country to send the invitations was taken to increase the participation rate. After completing the survey, participants were invited to forward the link to other CPP stakeholders. The questionnaire was anonymous, and all participants gave their informed consent at the beginning.

The online questionnaire was developed through RedCap 10.9.2 software (sections of the questionnaire are presented as supplementary material S1). It was presented in English and included closed- and open-ended questions to allow for characterization of stakeholders at national level. In this study, three questions from the survey were used in the study to evaluate the perceived primary role in change, proactivity, and influence of different sectors. Respondents were asked to rank the sectors (e.g., "Which sector do you consider that could



have a role in change concerning cancer primary prevention? Please rank from most important to less important."), and for the analysis, only the sector ranked first by each participant was considered.

Descriptive statistics were performed. Relative frequencies (%) were computed for each variable, and are presented for the total sample and stratified by country group (Western and Eastern). Statistical analysis was performed with R software.

#### Qualitative data

Semi-structured interviews were conducted to gain deeper insights into the specific roles of each sector in CPP. Purposive sampling was used, meaning that participants were selected through their expected capability to provide new points-of-view. This sampling method is commonly used in qualitative studies aiming to achieve diverse data (Ames, Glenton, Lewin, 2019). For both group of countries, we aimed to have a group of three participants from each penta-helix framework sectors. Thus, 30 interviews were expected, dependent on participants' availability willingness to participate, and saturation of information.

Partners of the 4P-CAN consortium were asked to provide a list of two/ three CPP stakeholders for each penta-helix sector, which would possibly be contacted, with a short description of their main activities. Portuguese research team in the 4P-CAN reviewed the information provided and selected potential participants according to their expertise and the needs of the study. The selection of participants prioritized the formation of a group with diverse perspectives and experiences, aiming the characterization of the sectors, and the possible identification of differences and similarities between Western and Eastern countries. The invitation email was prepared by the Portuguese team. Out of respect to confidentiality and personal information, a first invitation was sent by each partner to their suggested participants while the task leaders only contacted the participants upon their agreement that their contact details would be shared. This contact included an information sheet about the 4P-CAN project, the study goals and details concerning the interviews (e.g., request for recording the interview and handling of data), as well as an informed consent declaration.

The interviews were conducted online between July and September 2024, by four interviewers with previous experience with health-related semi-structured interviews. Before the interview started, the interviewer from Portuguese research team presented the main goal and explained in short what type of questions would be asked. The interviews were conducted following an interview guide (supplementary material S2), divided into four sections: (A) Introduction and characterization of the respondent, (B) Activities of the stakeholders, (C) Perceptions about other stakeholders, (D) and Interaction between stakeholders.



The interviews were partially transcribed. Their content was coded according to four categories: Activities, Motivations, Barriers and Opportunities. Thematic analysis was performed to identify, for each sector, common and relevant patterns of meaning (30), overlapping these four categories, considering the complexity and interconnectedness of ideas across the categories. For each sector, a general word summarizing the overarching themes was identified to encapsulate the central idea conveyed by the interview responses.



## Results

#### **Survey results**

A total of 110 stakeholders responded to the survey (Table 1). Of those, 56.4% were from Western countries. Around half of the participants (49.1%) were from the public sector, followed by 20% from academia/research, 23.6% from civil society, 4.5% from the media, and 2.7% from the private sector.

WESTERN EUROPE (n=48)		EASTERN EUROPE (n=62)	
Country	n	Country	n
Austria	1	Albania	1
Belgium	2	Bosnia and Herzegovina	1
Denmark	4	Bulgaria	8
Germany	1	Georgia	1
Greece	3	Kazakhstan	1
Italy	14	Lithuania	1
Malta	1	Montenegro	12
Portugal	15	North Macedonia	9
Spain	6	Poland	2
Sweden	1	Romania	7
		Slovenia	2
		Turkey	1
		Ukraine	16

Table 2: Characterization of participants of the survey: number of participants by country and country group.

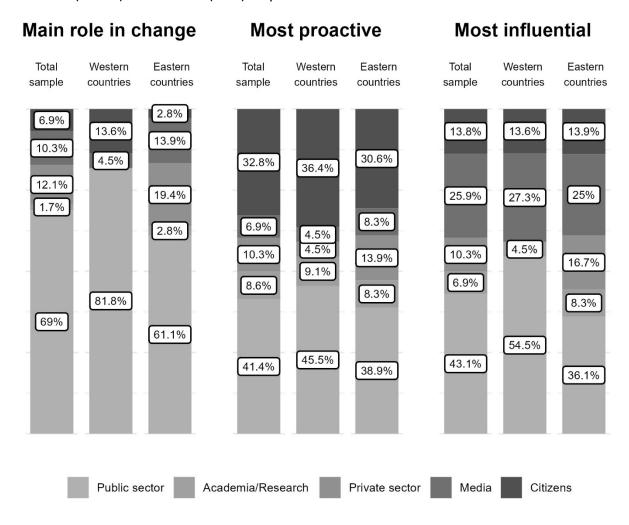
As depicted in Figure 1, the public sector was considered the sector with the main role in change by 69% of the total sample of participants. More than four-fifths of the participants from Western countries (81.8%) considered the public sector the one with the main role in change, compared to less than two-thirds (61.1%) of those from Eastern countries. The private sector (19.4%) and the media (13.9%) were the second and third most frequently cited sectors as the most important by respondents from Eastern countries. Civil society (13.6%) was the second most frequently considered by respondents from Western countries.

The public sector and the civil society were the two sectors more often considered the most proactive by both Western (45.5% and 36.4%) and Eastern respondents (38.9% and 30.6%). Among participants from Western countries, only 18.1% cited other sectors as the most proactive.

More than half of participants from Western countries (54.5%) rated the public sector as the most influential in their countries, compared to only 36.1% of those from Eastern countries.



The media was the second sector most frequently considered the most influential by both Western (27.3%) and Eastern (25%) respondents.



**Figure 2:** Results from the survey to CPP stakeholders. Percentage of participants identifying each of the five sectors (Public sector, Academia/Research, Private sector, Media, and Civil society) as having the main role in change, being the most proactive, and the most influential, shown for the total sample, and for respondents from Western and Eastern countries (%).

#### **Interviews results**

In total, we conducted 33 interviews to CPP stakeholders from nine European countries (Figure 2). Of those, 12 interviews were from Western countries and 21 with participants from Eastern countries (Table 3).



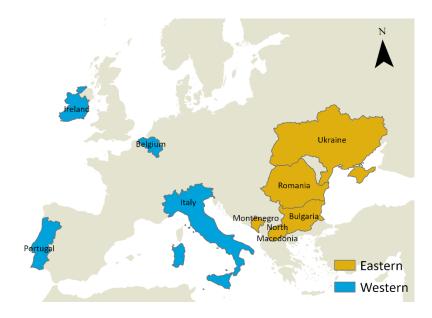


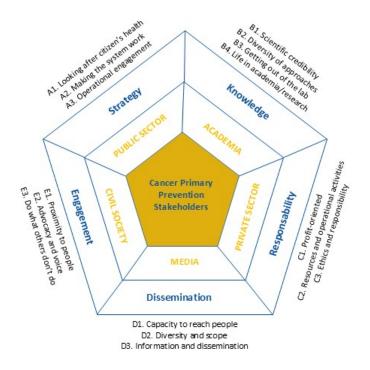
Figure 2: Countries of participants in the interviews.

		Western Europe	Eastern Europe
	Public Governance/ Public Sector	2	5
	Academia/ Research	2	3
SECTOR	Private Sector	3	5
	Media	2	3
	Citizens/ Civil Society	3	5
	Belgium	1	-
	Bulgaria	-	6
	Ireland	1	-
	Italy	5	-
COUNTRY	Montenegro	-	5
	North Macedonia	-	3
	Portugal	5	-
	Romania	-	4
	Ukraine	-	3

**Table 3:** Characterization of participants of the interviews: number of participants of the interviews by sector, country and country group.

The thematic analysis of the data obtained from interviews allowed to identify key themes of each penta-helix sector concerning their activities, motivations, barriers and opportunities (Figure 3). Each theme is presented in a narrative way, aiming to present the main ideas and avoid repetition between categories.





**Figure 3:** Themes and overarching concepts identified in the qualitative analysis for the five sectors (public sector, academia/research, private sector, media, and civil society)

#### **Public sector**

The word "<u>Strategy</u>" was identified as the overarching concept for the public sector, with three themes identified: "Looking after citizen's health"; "Making the system work"; and "Operational engagement" (Table 4).

Activities	Motivations	Barriers	Opportunities	
	A1. LOOKING AFTER	R CITIZEN'S HEALTH		
<ul><li>Complexity of players</li><li>Power</li><li>Strategic role</li></ul>	<ul><li>Responsibility and impact</li><li>Tackle burden of disease</li></ul>	<ul> <li>Political circumstances</li> <li>Threats to power</li> <li>Prevention not a priority</li> <li>Institutional barriers</li> </ul>	<ul> <li>Pivotal role in change</li> <li>Have a wider scope</li> <li>Gains in the long term</li> <li>Cooperation/ involvement</li> <li>Political opportunities</li> <li>Become more aware</li> </ul>	
	A2. MAKING TH	E SYSTEM WORK		
<ul><li>Epidemiology</li><li>Study what works</li><li>Provide structure</li></ul>	• Improve the system	• Structural issues • Insufficient data	<ul> <li>Create networks of professionals</li> <li>Write procedures</li> <li>International cooperation</li> </ul>	
A3. OPERATIONAL ENGAGEMENT				
<ul><li>Health education</li><li>Do screening programs</li></ul>	• Educate the population	<ul> <li>Lack of money</li> <li>People-related barriers</li> <li>Difficulties implementing</li> <li>Inequalities</li> <li>Human resources</li> </ul>	<ul><li>Deal with hierarchy</li><li>Extend the scope of activities</li></ul>	



Table 4: Overview of activities, motivations, barriers and opportunities, among public sector (A1 – A3).

#### Looking after citizen's health

The populations' health is often considered as the public sectors' main responsibility. To achieve this goal, there is a highly complex network of players, including local, regional, national and supranational institutions. These institutions can, at times, have difficult interactions between each other ("there is a conflict of interest between the different ministries"), with troubles communicating or sharing information.

The idea of power is often described, as the public sector is often described as having an influential and important role ("they have the tools and they have the power"). The public sector has financial resources, decides their allocation, while retaining legal power to produce change. Some of the barriers are related to limits to that power, for instance, when they are unable to fight lobbies from the industry. The position of power leads to the need of setting priorities and CPP (and in some cases, health in general) is not considered as such, compared to cancer treatment or other diseases ("most of the money goes to treatment, because it's very expensive").

Another activity is the definition of strategies (e.g., national plans against cancer) and setting agendas. The role of policymaker is also often connected directly with the public sector, responsible for developing policies and regulations to tackle modifiable factors ("not only to tax those risk factors, like tobacco smoking and alcohol").

The public sector is frequently described as intertwined with politics. CPP is often impacted by political instability or transitions of government ("they didn't continue the work that started. They want to start it again with new people"), something that can also be seen as an opportunity ("we have elections every two years [...], so it's a good thing"). Politicians' actions may be influenced by their ideology ("either from the left or the right, wants to impose their ideology"), and not be aware of the relevance of CPP, as some politicians are not from the health sector. Moreover, CPP does not seem to be a topic warranting political capital, as the effects are not visible in short time, and unpopular decisions would be needed ("it will be unpopular because you are trying to decrease some of the things that people like to do, like smoking and other stuff and the results will arrive many years later, when the politician that did this already went away").

#### Making the system work

Another facet of the public sector is providing structure to make the health system functional, focusing on its constant improvement. Several participants report that the public sector is involved in epidemiological research, providing and collecting data and doing health surveillance ("a situation analysis [...] will show us the clear situation"). This extends to



modeling the impact of policies, assessing and piloting new interventions ("if we do something related to prevention, primary care, etc., which will be the impact of these activities"), as well as consider the sustainability of the health system. Other activities include the consultation of experts, the creation of networks of professionals and the development of informatics technologies. Herein, participants report structural barriers of the public sector that affect their capacity to deal with cancer ("We don't have universal health coverage here"). One participant suggests writing procedures ("all these rules on paper"), while international cooperation is an opportunity, using tools from EU or following examples from other countries ("similar health system, [...] same population").

#### Operational engagement

Finally, the public sector is also involved in operational activities, closer to the populations, such as screening, health education ("we often use the setting of the cancer screening into our hospital [...] to promote good behaviors"), compiling scientific information, or building facilities for physical exercise. Some participants mention that translating policies into practice is difficult and too indirect ("they are not close to the people"), coupled with scarcity of financial and human resources. Implementation efforts also face difficulties from the population, such as low educational level, while some participants state how hard it is to tackle inequalities between groups and to reach disadvantaged populations.

#### Academia/Research

The word "Knowledge" was identified as the overarching concept for academia/research, with four themes being pointed out: "Scientific credibility"; "Diversity of approaches"; "Getting out of the lab" and "Life in academia/ research" (Table 5).

Activities	Motivations	Barriers	Opportunities		
	B1. SCIENTIFIC CREDIBILITY				
<ul><li>Trustworthiness</li><li>Knowledge creation</li><li>Scientific support to others' activities</li></ul>					
	B2. DIVERSITY	OF APPROACHES			
<ul> <li>Basic science</li> <li>Characterize the situation</li> <li>Project evaluation</li> <li>Innovation</li> </ul>	<ul> <li>Raise awareness to a difficult situation</li> <li>Lack of data</li> </ul>	<ul> <li>Financial barriers</li> <li>Human resources</li> <li>No clear direction</li> <li>No resources/ no equipment</li> <li>Limited scope</li> </ul>	<ul> <li>Expand the scope of research</li> <li>Multidisciplinary/ integration</li> <li>International cooperation</li> <li>Increase support resources</li> </ul>		
B3. GETTING OUT OF THE LAB					



<ul><li>Teach/ train</li><li>Write guidelines</li><li>Education at schools</li></ul>	• Empower people • Get down the cancer/ current state	• Isolation/ no collaboration	<ul> <li>Make research more visible</li> <li>Propose policies</li> <li>Do training for other sectors</li> <li>Leave the bubble</li> </ul>
<ul> <li>Academic cooperation</li> <li>Step in the career of people from other sectors</li> <li>Meetings/ networks</li> </ul>	<ul> <li>Scientific interest</li> <li>Get funding</li> <li>Contamination between areas</li> </ul>	<ul> <li>Methodological aspects</li> <li>Journals not interested</li> <li>Difficulties finding financing</li> <li>Focus on metrics</li> </ul>	• Leave the bubble

Table 5: Overview of activities, motivations, barriers and opportunities, among academia/research (B1 - B4).

#### Scientific credibility

The idea of credibility and trustworthiness is often used to describe the activities of academia/research. Information coming from academia/research is received with acceptance and researchers can be regarded as sources of authority. One of the goals of academia is to build knowledge, relying on robust methods and previous evidence ("looking at the prevalence of cancer and how at a science, biological, medical, physiological, psychological, behavioral aspect that we can target cancer, but also prevent the prevalence of cancer"), and looking for scientific consensus. This information can inform stakeholders, influencing the activities of other sectors. For instance, the public sector may rely on research evidence to design policies, while the civil society may use data to sustain their advocacy activities.

#### Diversity of approaches

Participants describe a wide scope of activities, ranging from characterization to innovative approaches to prevention. Some participants are involved in epidemiological research, noticing the lack of previous data and aiming to characterize the situation in their countries to raise awareness to CPP ("it basically means that primary prevention, it's not working well"). Other participants combine their activities with basic science research or aim to connect that with CPP. Other research activities include finding innovative ways to disseminate messages to promote change, such as testing apps or using media channels ("we could try to convey these messages on a different perspective using entertainment education").

Notwithstanding, barriers as scarcity of financial and material resources hinder the development of some activities, as well as the overload of human resources ("everything just ends up on the shoulders of two to three people"). Some participants mention the need to widen the scope, noticing a small number of activities and research groups. A clear definition of priorities also seems to be missing ("we are navigating without the compass in this area") and lack of data hinders the definition of goals. The collaboration between different



institutions is described as an opportunity, namely cooperation between different sectors and disciplines, both nationally and internationally.

#### Getting out of the lab

Researchers can play an active role outside research or academia can work to apply its findings. Some participants describe teaching and getting involved in the training of health professionals. Some researchers mention being involved in health education activities in the community ("education at schools and companies, community services, [...] charities"). Researchers can also work to apply research and create resources for other sectors, for example, by creating educational programs or drawing guidelines. The motivation for some researchers is to educate and empower the population and use the existent knowledge to tackle the burden of cancer and the overload of healthcare services. This movement of sharing with the community can be hindered by the isolation of researchers and some difficulties collaborating with others ("academia is for academia, [...] it's not for normal people").

#### Life in academia/research

Some descriptions about the participation of academia/research in CPP can be framed within the specific way academia works. Holding conferences, networking and doing consultancy for other research projects are mentioned as activities, as well as cooperating with other universities or research centers. Academia is often a step in the career of people from other sectors, for instance, one participant from the public sector is doing a Ph.D. about cancer screening, while others try to incorporate research in their jobs ("[we are] very involved in academic research activities for the dissemination of our results"). Scientific curiosity has been described as motivation, as well as invitations by other researchers and the evolution of personal scientific interests.

Participants also described some difficulties doing research about CPP, namely the fact that there are methodological difficulties, it takes time and is expensive. One participant described how hard it is to build a career in research, while another reports that scientific journals are not particularly interested in this topic. The difficulties finding funding are often reported, accentuated by the difficulty in fitting CPP research topics in the existing financial calls ("this middle ground, this area that's a little bit grey in terms of research"), and the lack of interest from the funding agencies. Doing research is easier when financial support is not needed ("these epidemiological studies [...] have the smallest number of barriers"). One participant describes that academia often changes its focus and structure according to funding.



#### Private sector

The word "Responsibility" was identified as the overarching concept for the private sector, with three themes: "Profit-oriented"; "Resources and operational activities"; and "Ethics and responsibility" (Table 6). Several participants from other sectors reported that the private sector is not interested in CPP, which is in contrast with the descriptions from the participants in this sector, that often perceive it as very proactive and having large potential.

Activities	Motivations	Barriers	Opportunities
	C1. PROFIT	-ORIENTED	
<ul> <li>Development of products/ innovation</li> <li>Activities dependent on their objectives</li> </ul>	<ul><li>Profit</li><li>Limited interest</li><li>Marketing and image</li><li>Own agenda</li></ul>	<ul> <li>Focus on profit</li> <li>Insufficient involvement</li> <li>Lack of return</li> <li>Limited scope/ inequalities</li> </ul>	<ul><li>Clear message/ build their reputation</li><li>Red lines</li><li>Regulations</li></ul>
	C2. RESOURCES AND OF	PERATIONAL ACTIVITIES	
<ul> <li>Providing resources</li> <li>Support others' activities</li> <li>Raise awareness</li> <li>Vaccination/ screening</li> <li>Capacity to reach people</li> </ul>	<ul> <li>Educate and promote health of people/ change mentalities</li> </ul>	<ul><li>Bad reputation</li><li>Conflict of interests</li><li>People's beliefs</li></ul>	<ul> <li>Expand activities/ think outside the box.</li> <li>Geographic and sociodemographic outreach of pharmacies</li> <li>Pharmacies' collaboration with research</li> </ul>
	C3. ETHICS AND	RESPONSIBILITY	
<ul> <li>Promote the health of the employees (included in general health promotion)</li> </ul>	<ul> <li>Personal reasons</li> <li>Capacity to prevent cancer</li> <li>Ethical concern/ responsibility</li> </ul>	• They put pressure on the government by pressuring citizens.	<ul> <li>Be responsible selling products</li> <li>Companies as a concentration of people</li> </ul>

**Table 6:** Overview of activities, motivations, barriers and opportunities, among private sector (C1 – C3).

#### **Profit-oriented**

The private sector is described by most participants as having profit as their main motivation ("you need to earn money to give back something to the society"). This impacts their level of involvement in CPP ("in principle, that is not their core business"), as well as the activities wherein they are involved ("I always smell some kind of, you know, thirst for profit"). For example, pharmaceutical companies may only focus on one type of cancer or may refuse to be involved when there is no financial return. It has also been described their involvement in activities for marketing purposes, or to restore their reputation, with no substantial effects ("they're trying to show that they care without actually caring about this type of things"). This focus on profit is also related to investments in innovation and the development of new products ("they are the ones that developed the vaccines"). This may create a conflict of interests, something that can be tackled through regulations, already in place in some countries, while other participants report that a collaboration is possible when trusting



relationships are built and limits are defined ("we have to have some red lines and to have a very good framework how to work with them").

#### Resources and operational activities

The private sector is described as having resources that can be used to support other sectors. Some private companies develop and support awareness campaigns, with the goal of empowering people and changing mentalities ("changing the mindset and educate people with the benefits of vaccination and primary prevention"), while the operational collaboration in vaccination and screening has also been mentioned. Their resources are also used to increase the outreach to the public ("They have good social media managers").

Their activities are, notwithstanding, limited by their bad reputation ("[in this country] we look at the private sector as an evil thing"), regulations and the contextual perception of priority ("there were other diseases that were more important for the society"). Participants from the private sector reported that they are willing to extend the scope of their activities ("thinking outside of the box and finding ways to get closer to the public"), for instance, by expanding their educational activities to children, working with cancer survivors, focusing hereditary, or fighting societal stigma about cancer.

Pharmacies, as part of the private sector, were also acknowledged for their role in operational activities (e.g., smoking cessation initiatives). They bring unique strengths, including broad geographical reach, the ability to connect with diverse sociodemographic groups, and to collaborate with other sectors (e.g., help with research).

#### **Ethics and responsibility**

Participants from the private sector may pursue CPP activities by ethical concerns ("when you do a good deed, you feel proud"), along with personal reasons ("we all have cancer patients in our families"). The burden of cancer (actual and predicted) and the possibility to make a difference with the knowledge that already exists are also mentioned as motivations.

Some participants reported that the private sector has a major role in change, considering that they sell products that are harmful, although a meaningful change is not expected. This idea is complemented by describing some companies in positions of power ("the food industry is very, very strong and very, very rich"), that makes them harder to be regulated, as well as putting pressure on the public sector and citizens ("with all sorts of arguments, such as that they help the economy or they start with saying that their products are not harmful, that people should be free to choose"). A stronger regulation for advertisement is an opportunity to create some change.



The role of private companies promoting the health of their employees has been extensively described by one participant, considering that approaching people in their employment is an opportunity to reach a large number of people. This company gets involved in regular information campaigns for promotion of healthy diet and physical activity, as well as screening activities. That is considered an opportunity to create healthy habits that may be replicated in their homes, by their families. This idea is repeated by other participants, who highlight, for instance, that employers can provide incentives to cancer prevention ("half a day off, a day off for screening procedures").

#### Media

The word "Dissemination" was identified as the overarching concept for media. Three key themes were identified for media: "Capacity to reach people"; "Diversity and scope"; and "Information and dissemination" (Table 7). Most participants described the media sector as important and influent. Its power and potential in CPP are widely recognized, although several participants report that more can be done.

Activities	Motivations	Barriers	Opportunities	
	D1. CAPACITY TO	D REACH PEOPLE		
<ul> <li>Great impact</li> <li>Place to influence people/ policy</li> <li>Create awareness</li> </ul>	<ul> <li>Pressure policies</li> <li>Public service</li> <li>Dubious motivations</li> <li>Commercial interests</li> </ul>	<ul> <li>CCP not a priority</li> <li>Influence by politics</li> <li>Compliance with news cycles</li> <li>Bad reputation</li> <li>Conflicts of interest</li> </ul>	<ul> <li>Powerful tool</li> <li>Adjust the dialogue</li> <li>Choose the best channels</li> <li>Impact policies</li> <li>Two sides of the story</li> <li>Public perception change</li> </ul>	
	D2. DIVERSIT	Y AND SCOPE		
<ul><li>Different channels, including new media</li><li>Diversity of topics and activities</li></ul>		<ul> <li>Channels not trustable</li> <li>Sources not trustable</li> <li>Online commentaries</li> <li>Lack of in-depth focus</li> <li>Too many scopes</li> </ul>	<ul> <li>Visibility given by new media</li> </ul>	
	D3. INFORMATION AND DISSEMINATION			
<ul> <li>Provide information</li> <li>Disseminate specific news</li> <li>Interaction with other sectors</li> </ul>	<ul> <li>Educate the public</li> <li>Responsibility</li> <li>Personal experiences</li> <li>Interesting topic</li> </ul>	<ul> <li>Responsibility not fulfilled</li> <li>Unprepared journalists</li> <li>Low quality of information</li> <li>Lack of resources</li> </ul>	<ul> <li>Adjust the messages</li> <li>Send the right messages</li> <li>Training for journalists</li> </ul>	

**Table 7:** Overview of activities, motivations, barriers and opportunities, among media (D1 – D3).

#### Capacity to reach people



Media's influence is related to the ability to reach people, from different sociodemographic groups ("from children to the older age"), through several media channels. This reach includes persons without disease that may be less aware of cancer and can largely benefit from CPP ("because when we have the disease, [...] you are more aware").

Media may affect people's health behaviors ("they diffuse the communication about good or bad lifestyle") and part of their role includes raising awareness and educating people for CPP ("to take the plans and the programs and the strategies to the common citizen"), thus influencing public perception and the search for solutions ("when the problem is secret [...], the problem will remain the problem"). Pressuring political action is also reported as a motivation ("that maybe we can put some pressure sometimes when politicians and politics are not following the needs, the societal needs").

Despite this, several participants reported that CPP (or health in general) is not a priority for media ("this type of subjects does not sell papers") the coverage is not made with enough depth, and is often overlooked by the news cycle, or sensationalistic trends ("some patient died in a hospital yard"). Sometimes the interest in covering CPP is circumscribed to a specific event, issue ("how could the presence of a military base [...] influence the incidence of cancer") or periods. Extending coverage besides awareness months has been suggested, as well as the need to adapt the messages ("you need to find what is exciting for the public").

While reaching a large amount of people, there are other barriers related to conflicts of interest ("the line between news and advertising is a very thin line"), political interference and bad reputation ("they think that we are sharks"), that may hinder the collaboration of other professionals. Listening to different perspectives may help dealing with these issues. Some participants report issues trusting professionals and feeling forced to comply with their narratives ("they seem to have really the answers to their questions already framed in mind"), but this relationship can be developed ("know how to talk to them").

#### Diversity and scope

Participants reported a wide variety of media channels (e.g., television, blogs, podcasts). This diversity allows the conduction of different activities, that range from debates, interviews with specialists and researchers, and messages for cancer prevention awareness. Some participants report more innovative ways to send messages, as a fictional tv-show about cancer prevention ("a different perspective using entertainment education") or creative content in social media ("short videos like reels"). This diversity makes it possible to reach several groups ("some people listen more to radio, some other to television, some other [...] go to the stadium").

A special focus was spoken about social media and influencers, that are often referred to as disseminating low quality information. On the other hand, social media is also described as a



positive way to share stories ("people who have cancer and who decide to be a blogger or an influencer or a YouTuber, to tell their story and to influence positively others to take care of their health"). These new media channels also create new challenges to be tackled, such as online commentaries ("the commentary is sometimes bad [...], it's like a bit complicated"). One participant reported the complexity of managing different scopes and public ("there is a balance between the knowledge sharing that we do at an EU level, the knowledge sharing that we are doing [at a country level]").

#### <u>Information and dissemination</u>

The dissemination of specific information to the public is a major activity of the media. That seems to be advantageous, as it is a rapid way to share information, and it can be stored and accessed in any time ("it stays on our website"). This capacity can be used to disseminate particular news, such as the launching of national cancer plans, or official campaigns from the health authorities. Moreover, they can disseminate what other sectors do.

Low quality of information is a relevant barrier when describing media's actions, specially (but not exclusively) new media channels ("Some influencers say [...] shouldn't use them [sunscreen products]"). In some cases, communication can be done by non-specialized human resources ("often the medical doctors think that they can do the communication by their own"), and journalists are not always aware, or do not have the knowledge to share the most certain information. This can be tackled through specific training ("so journalists also have to be educated how to report to public regarding disease awareness").

Some participants highlight that media can facilitate awareness campaigns ("they give us [civil society] free space to do our campaigns") and limit the advertisement for unhealthy products.

#### Civil society

The word "Engagement" was identified as the overarching concept for civil society, with the following themes: "Proximity to people"; "Advocacy and voice"; and "Do what others don't do" (Table 8).

CIVIL SOCIETY					
Activities	Motivations	Barriers	Opportunities		
E1. PROXIMITY TO PEOPLE					
<ul> <li>Participation of persons from other sectors</li> <li>Personal involvement</li> <li>Proximity to people</li> </ul>	<ul> <li>Personal involvement besides one's job</li> <li>Personal experience</li> <li>Change public perceptions</li> </ul>	<ul> <li>Lack organization/ lack strength/ lack power</li> <li>Disregard by others</li> <li>No expertise</li> <li>Stigma/ cultural issues</li> <li>People-related barriers</li> </ul>	<ul> <li>Changes in structure.</li> <li>Lawyer</li> <li>Joining forces</li> <li>Advocacy/ strength to change things</li> </ul>		



E2. ADVOCACY AND VOICE					
<ul> <li>Influence and advocacy</li> <li>Personal history as their voice</li> <li>Central part in the health system</li> </ul>	<ul> <li>Burden of cancer</li> <li>Sensibilize the population</li> <li>Inefficiency of the government</li> </ul>	<ul> <li>Lack of awareness</li> <li>Insufficient involvement from civil society/ not a lot of patient organizations</li> <li>Isolation/ no visibility</li> </ul>	<ul> <li>Expand activity</li> <li>International cooperation</li> <li>Fill the needs</li> <li>Opportunities to educate/ raise awareness</li> </ul>		
E3. DO WHAT OTHERS DON'T DO					
<ul><li>Education/ awareness</li><li>Filling the gaps</li><li>Extensive scope of activities</li></ul>		<ul><li>No defined strategy</li><li>Lack of resources</li><li>Limited scope</li><li>Overlapping services</li></ul>			

Table 8: Overview of activities, motivations, barriers and opportunities, among civil society (E1 – E3)

#### Proximity to people

The idea of proximity is relevant when describing civil society, having less formal approaches that may more easily reach people, bridge policies and individuals and promote change. This can also be seen in the motivations of people from this sector, who report personal or familiar experiences with cancer. Some participants from other sectors also volunteer in civil society associations, while one participant has taken several positions in different sectors attending to their private interest in CPP. Another participant reported a personal will to engage in CPP in their private life besides their activities on the private sector ("I will set an example for my kids, for my family and for the people close to me"). Being close to people makes them more prone to experience individual and cultural barriers, such as low educational level of persons, stigma ("people don't want to speak about cancer") and societal values ("when speaking about altruism, [...] we're on the true bottom of the list"). On the other hand, citizens and civil society may have too informal approaches, lacking organization ("they are very scattered and they are fragmented"), expertise and power ("they may generate a big fuss, but nothing really moves, nothing really changes"), and may be disregarded by persons from other sectors.

#### Advocacy and voice

Citizens and civil society have an important voice that is described as a central part in CPP ("I think that without civil society, without citizens, we cannot do anything") and, overall, the health system ("they are the first stakeholder of the system") and have an important role in change ("those that can move the needle"). Civil society's voice can communicate particular needs, push the agenda, change public perceptions, influence the allocation of resources, inform specific policies and help implement them ("if you don't have the civil society with you, it's only a plan"). Some participants described this strong voice as lobbying ("citizen associations that can lead to create a lobby industry"). Particularly, the perspectives of cancer



survivors seem to have a great influence and may set examples for other citizens ("give testimonies that impact other people's choices and behaviors").

In opposition to this agency, some civil society organizations may not yet have found out the importance of prevention or may consider it less priority than treatment. Some participants from other sectors report that the involvement of civil society is insufficient, there are two few organizations ("if you look at [...] organizations that are non-profit [...], you don't have many related with cancer. They [survivors] just want to live"), or their work is not visible enough. Some changes are suggested to facilitate their work, such as developing partnerships, creating federations and changing structure investing in human resources ("it would be nice to have a patient representative who is actually a lawyer").

#### Do what others don't do

Civil society is involved in a large scope of activities, that often fill the gaps of other sectors. Some participants mentioned civil society to do activities to increase awareness, sensibilize and empower the population. This includes going to schools to reach young people ("students already in high school [...], I knew that they were already smoking [...]"), with adapted messages ("you wanted to be independent and autonomous, but when you start smoking, you start to be exactly the opposite"), that may have stronger effects that those from their families. Other activities include creating networks to increase collaboration between doctors and experts, organizing screening programs and seeking fundraising. Some participants from this sector also report being involved in European projects, and the potential of contacting patient organizations from other countries has been highlighted. The motivation to pursue these activities often comes from noticing the burden of cancer, and some inefficiency from the government ("waiting for the government to organize something") that has difficulties in implementation ("a huge gap within the implementation of Europe's beating cancer plan").

However, it is mentioned that the scope of these activities could be enlarged ("we should be doing more and better") and that the lack of resources, especially financial resources, interferes with the execution of more activities. One participant mentions the inability to reach those that could have more benefits from public health programs, while another states that there is some overlapping with services from the municipality. Several opportunities to expand the activities of civil society have been described, including organizing more events, getting more involved in policy or educating journalists on the importance of primary prevention.



#### Iron Curtain of Cancer Cases

While the qualitative thematic analysis did not reveal meaningful differences between Western and Eastern countries, participants from Eastern Europe highlighted some barriers and opportunities that may potentially be tackled to reduce regional disparities. Participants from Eastern European countries noted that public sector actions are often deprioritized due to financial constraints ("there is always financial problems, political problems, foreign political problems, but healthcare was put aside"), frequent governmental changes, and political instability ("we have really frequent changes of government [...] you are starting from scratch"), which together disrupt continuity in health initiatives. This environment often results in outdated practices with minimal data-driven support. Furthermore, participants highlighted a lack of cooperation among government agencies, academic institutions, and NGOs, which hinders the collaborative efforts necessary for effective CPP implementation. Despite these barriers, there is a recognized desire within Eastern European academia to produce epidemiological evidence to advocate for CPP ("So we just thought it would be a good basis to see where we are. And the results are so devastating. And so they can serve as a good fundament"), with participants acknowledging the value of such data as a solid foundation for policy advocacy.

The small dimension of some countries impacts the scope of activities that are pursued by the different sectors. For instance, one participant working on the pharmaceutical industry mentions that there is no representative office of their company in the country, and that makes them more dependent of external entities. This is also seen among civil society with reports of only a few patient organizations, and some difficulty in being a united front. Collaborating internationally is often described as an opportunity, for instance, by joining EU ("we want to be a member of EU. So as a candidate member of EU, we want to be more proactive in this issue"), by participating in EU-funded projects, or replicating good examples from other countries.

These results suggest that, while sample limitations exist, insights from Eastern European perspectives offer a clearer view of the systemic and collaborative challenges affecting CPP, underscoring the importance of both political stability and intersectoral partnerships for impactful cancer prevention policies.

## **Discussion and conclusions**

This study uses both quantitative and qualitative data to characterize the role of stakeholders from the public sector, academia/research, private sector, media and civil society in CPP, and to identify possible differences explaining the Iron Curtain of Cancer Cases. Quantitative results show that the public sector is considered the key driver of change, the most proactive and the most influential, but the proportion is larger among Western than Eastern European



countries. Qualitative results support that the five sectors have different yet complementary roles in CPP. While motivations and barriers do not seem to differ between Western and Eastern countries, data show relevant opportunities for Eastern countries.

#### **Characterization of CPP stakeholders**

Key findings of this study suggest that the public sector is often expected to create a strategy and to build a structure, and a meaningful gap is felt when that role is not fulfilled. Participants emphasize the connection between the public sector, politics, and cancer prevention, highlighting that politicians may lack awareness, show little interest, or fail to ensure continuity during periods of political transition. Despite their importance, prevention efforts often fail to generate political capital, as their benefits are less tangible and immediate compared to other policy areas. A future study may explore the possible association between political instability and CPP indicators, while future qualitative research with politicians may collect data on how to build consensus and make CPP a political priority.

Academia/Research can build important knowledge to guide CPP and to support the activities from other sectors, for instance, by quantifying risks for specific exposures, and testing CPP interventions. Still, doing research about CPP can be methodologically demanding and multidisciplinary involvement may be required. Quantifying the benefits of CPP interventions may be crucial to inform politicians about potential savings, or to raise awareness in society. Moreover, results from our study show how CPP research may be difficult to frame within existent financial calls, highlighting the need for more targeted funding opportunities to support this critical area.

CPP initiatives may face resistance in the private sector due to conflicting commercial interests. Still, the private sector can offer financial support and non-financial resources, such as expertise and visibility. Participants highlight the need to have responsible actions from the private sector, for instance by adjusting their sells, or doing health promotion activities with their employees. Moreover, some traditional media channels may prefer more sensational and shocking events. The development of short courses for journalists might provide them additional knowledge cover CPP.

Civil society has an important role advocating for CPP, being closer to people. Yet, their approaches can be too informal and their actions may struggle with structural issues and the scarcity of resources. Some participants report a lack of involvement from civil society, a small number of associations or a lack of focus in CPP, compared to other areas of the cancer continuum. Addressing this issue could require support from other sectors, such as the public sector providing a well-defined and transparent set of priorities. Some civil society associations lack expertise, a challenge that can be tackled by fostering collaborations with high-level institutions, such as those operating at the European level.



#### **Iron Curtain of Cancer Cases**

Quantitative data suggest that countries from Eastern Europe may turn to different sectors of society as a way to deal with inefficiency of public sector. Qualitative data show that there is limited involvement from the public sector in Eastern countries, while the other sectors expect them to lead and to set strategies and help the overall collaboration between partners. Results for Eastern countries call for availability of epidemiological data, to assess the current situation and to better define the potential gains obtained by developing cancer prevention. Countries from Eastern Europe can also benefit from international collaborations, whether by joining EU projects or learning from the example of other countries, particularly smaller ones. These smaller countries, due to their size, often face constraints not only in market dynamics but also in areas such as research capacity, policy implementation, and healthcare infrastructure. By observing how these countries have overcome such challenges, Eastern European nations can adopt innovative solutions tailored to their own contexts.

#### **Merits and limitations**

In this study, we were able to use a diverse sample of participants, from different countries, sectors, and scope of activities. All participants were asked about their own activities, and about the role of other sectors, thus allowing different points of view, avoiding the possible bias of a participant overestimating the work done by their own sector. While the penta-helix provides a useful classification of stakeholders for CPP, the identification of the sector of some stakeholders proved difficulty, due to overlapping areas (e.g., non-profit associations representing private companies) or change of sectors during one's professional career. English language was used in all data collection methods, even though the participants in this study were predominantly non-native speakers. This may have led to selection bias, since those willing to participate must have best command of the English language than non-participants and may be more likely to collaborate in international projects or read international scientific literature. While this study did not allow country-specific characterization of stakeholders, replicating this approach at a country-level will extract more comprehensive knowledge useful for the design and implementation of country-tailored policies.

#### **Conclusions**

In conclusion, this study provides evidence on how CPP goes beyond the National Cancer Control Programmes. In order to unravel the full potential of CPP decreasing the burden of



cancer, an appropriate interaction and complementary between stakeholders from different sectors is desired.



### References

- 4P-CAN Project. [Internet]. [cited 2024 Sep 9]. Available from: <a href="https://4p-can.eu/">https://4p-can.eu/</a>.
- Akselrod S, Collins TE, Berlina D, De Pinho Campos K, Fones G, de Sousa Neves D, et al. Multisectoral action to address noncommunicable diseases: lessons from three country case studies. Front Public Health. 2024 Feb 21;12.
- American Cancer Society. The cancer Atlas. Most commonly diagnosed cancers in Europe among males and females; 2018. [Internet]. [cited 2024 Oct 27]. Available from: <a href="https://canceratlas.cancer.org/the-burden/europe/">https://canceratlas.cancer.org/the-burden/europe/</a>.
- Ames H, Glenton C, Lewin S. Purposive sampling in a qualitative evidence synthesis: a worked example from a synthesis on parental perceptions of vaccination communication. BMC Med Res Methodol. 2019; 19(26).
- Arnold M, Karim-Kos HE, Coebergh JW, et al. Recent trends in incidence of five common cancers in 26 European countries since 1988: Analysis of the European Cancer Observatory. Eur J Cancer. 2015;51(9): 1164–87.
- Espina C, Porta M, Schüz J, Aguado IH, Percival RV, Dora C, et al. Environmental and occupational interventions for primary prevention of cancer: a cross-sectoral policy framework. Environ Health Perspect. 2013 Apr;121(4):420-6.
- Ferlay J, Colombet M and Bray F. Cancer Incidence in Five Continents, CI5plus: IARC CancerBase No. 9. Lyon, France: International Agency for Research on Cancer; 2018. [Internet]. [cited 2024 Oct 27]. Available from: http://ci5.iarc.fr.
- Ferlay J, Colombet M, Soerjomataram I, et al. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries and 25 major cancers in 2018. Eur J Cancer. 2018; 103:356–387.
- Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, Piñeros M, Znaor A, Soerjomataram I, Bray F. Global Cancer Observatory: Cancer Today (version 1.1). Lyon, France: International Agency for Research on Cancer; 2024. [Internet]. [cited 2024 Oct 27]. Available from: https://gco.iarc.who.int/today.
- International Agency for Research on Cancer (IARC). Cancer Mortality Database. Lyon, France: International Agency for Research on Cancer; 2024. [Internet]. [cited 2024 Oct 27]. Available from: <a href="http://www-dep.iarc.fr/WHOdb/WHOdb.htm">http://www-dep.iarc.fr/WHOdb/WHOdb.htm</a>.
- Santucci C, Patel L, Malvezzi M, Wojtyla C, La Vecchia C, Negri E, Bertuccio P. Persisting cancer mortality gap between western and eastern Europe. Eur J Cancer. 2022; 165:1-12.



- Schüz J, Espina C, Wild CP. Primary prevention: a need for concerted action. Mol Oncol. 2019;13(3):567-578.
- Schüz J, Espina C, Villain P et al. European Code against Cancer 4th Edition: 12 ways to reduce your cancer risk. Cancer Epidemiol. 2015;39 (1)S1-10.
- Sudiana K, Sule ET, Soemaryani I, Yunizar Y. The development and validation of the Penta Helix construct, Verslas: Teorija ir praktika / Business: Theory and Practice; 2020.
- Vineis P, Wild CP. Global cancer patterns: causes and prevention. The Lancet. 2014; 383 (9916) 549 557.
- Wild CP, Weiderpass E, Stewart BW, editors. World Cancer Report: Cancer Research for Cancer Prevention. Lyon, France: International Agency for Research on Cancer; 2020. [Internet]. [cited 2024 Oct 27]. Available from: <a href="http://publications.iarc.fr/586">http://publications.iarc.fr/586</a>.
- World Health Organization. National cancer control programmes: policies and managerial guidelines, 2nd ed. World Health Organization; 2002. [Internet]. [cited 2024 Oct 27]. Available from: <a href="https://iris.who.int/handle/10665/42494">https://iris.who.int/handle/10665/42494</a>.



# **List of Supplementary Materials**

**\$1:** Survey Questionnaire

**S2:** Interview Guide



## <u>S1</u>

## **SURVEY QUESTIONNAIRE**

#### **CHARACTERIZATION OF CPP STAKEHOLDERS**

- 1. What is your country?
- 2. When answering this survey, do you consider yourself as:
- Citizen and/or Patient
- Health Professional
- Researcher/Academician
- Health Administrator
- Health Authority / Policy or Decision Maker
- Cancer prevention/health advocate
- Staff of International organization or agency
- Other:
- 3. What is the main research / professional field you are active in?
- 4. To what extent are you engaged in primary cancer prevention (from 1 to 10, meaning 1 no engagement)?
- 5. In which geographic area is your activity developed/concentrated? (National/European/International/Other?)
- 6. What is your specific role at the national level in Cancer Primary Prevention and/or Non-communicable diseases prevention (NCDs) (e.g. policy creator, leading initiatives such as..., legislator, activist etc.). Provide as many details as possible.

#### **QUESTIONS ON CPP STAKEHOLDERS**

- 1. Do you or your organisation collaborate with other key national actors on cancer primary prevention? If so, please specify.
- 2. Which sector do you consider that could have a **role in change** concerning cancer primary prevention? Please rank from most important to less important, being 1 the most important.



- Public Governance/public sector
- Academia/ research
- Private sector
- Media
- Citizens/Civil Society
- 3. Which sector do you consider to be **the most proactive** in addressing cancer primary prevention in your country? Please rank from most proactive to least proactive, being 1 the most proactive.
- Public Governance/public sector
- Academia/ research
- Private sector
- Media
- Citizens/Civil Society
- Other (Which one(s))
- 4. Which sector do you consider to be **the most influential** in addressing cancer primary prevention in your country? Please rank from most influential to least influential, being 1 the most influential.
- Public Governance/public sector
- Academia/ research
- Private sector
- Media
- Citizens/Civil Society
- Other (Which one(s))
- 5. In your opinion, which of the above-mentioned **sectors best interact together** to address cancer prevention in your country?
- 6. At the European level, please name and provide contact information (if possible) of up to 5 organisations you consider to be major stakeholders in the cancer primary prevention field.
- 7. At the International level, please name and provide contact information (if possible) of up to 5 organisations you consider to be major stakeholders in the cancer primary prevention field.



# <u>S2</u> INTERVIEW GUIDE

#### **BACKGROUND**

This document describes the protocol for performing semi-structured interviews to stakeholders working on cancer primary prevention in Europe.

These interviews are framed within the 4P-CAN project, funded by the European Commission under the Horizon EUROPE Programme 2021-2027 (MISS-CANCER-01). The 4P-CAN project aims to understand barriers (legislative, socio-economic, commercial, or behavioral) in the adoption of cancer primary prevention measures. The project takes into account the gap between Western and Eastern European countries in cancer incidence and mortality rates, that makes cancer primary prevention measures a major priority in Eastern countries.

In these interviews, the goal is to shed new light into this *Iron Curtain of Cancer Cases*, by characterizing stakeholders from different sectors, identifying challenges and opportunities in their actions, and understanding interactions between different sectors.

Participants were identified by the partner institutions from 9 European countries as stakeholders involved in cancer primary prevention in their countries. In light of the goal of the study, each participant is classified according to their country group: Western (Belgium, Italy, Portugal) vs Eastern (Bulgaria, Montenegro, North Macedonia, Romania, Ukraine) European countries. Moreover, participants were classified within one of sectors (following a penta-helix approach): public governance, academia/ research, private sector, media or citizens/ civil society.

Using semi-structured interviews is a common approach when doing qualitative health-related research. In a semi-structure interview, there is a rigid structure that can be varied according to the study purpose and research questions, combining the process of a formal interview with a conversational style that allows the exploration of a particular topic. This interview guide covers the main topics of the study, providing a structure for the discussion. Yet, this structure must not be followed strictly, and can be adapted according to the participant, and the themes emerging during the conversation<sup>1</sup>.

#### **GOALS**

 $<sup>^1</sup>$  For instance, when a participant introduces new information, the interviewer can make new follow-up questions, to get a deeper insight on that idea. On the opposite, when a participant does not seem comfortable exploring a specific topic, that can be shortened. Deliverable 2.2-4P-CAN



- **1.** To characterize cancer primary prevention activities from stakeholders of different sectors (public sector, academia, private sector, media and civil society);
- 2. To identify challenges and opportunities in stakeholders' actions;
- **3.** To understand interactions between stakeholders from different sectors.

#### **TOPICS FOR DISCUSSION**

#### A. INTRODUCTION

- Thank for accepting our invitation to participate in this interview from the 4P-CAN Project.
- I'm a researcher from the Portuguese partner of the 4P-CAN project (National Institute of Health Doctor Ricardo Jorge).
- This project is funded by the European Commission and is a collaboration between 17 organizations from 11 different countries. The primary objective of this study is to gain a comprehensive understanding of the barriers hindering cancer primary prevention.
- I should inform you that your participation is voluntary, and you can decide to stop your participation at any time.
- I will start recording the session and ask you to please give permission in the message that will appear on your screen.
  - [Recording the interviews allows us to gather more complete information and facilitates a more fluid conversation without spending excessive time taking notes. Afterward, the interviews will be transcribed by the researchers involved in this task (the Portuguese team from the 4P—CAN consortium). No identifiable data will be shared with other project partners or members of the public. The final product of this study will be disseminated through scientific reports and may be presented at conferences. The dissemination of the results will include only anonymous, non-identifiable information.]
- You have been identified as a cancer primary prevention stakeholder by one of the partners in our research study. A stakeholder is a person with an interest or concern on something.
- 1. In which sector are you involved? [Share the slide with the sectors]
- **2.** Could you please specify better how you are involved in Cancer Primary Prevention as a stakeholder as an individual or on behalf of an institution?
- **3.** What is the main institution where you carry out cancer primary prevention activities? [Collection of data about the participant and their institution that confirm their categorization in the proposed sector]

#### B. ACTIVITIES



- 4. In which main cancer primary prevention activities are you involved?
- 5. Are you satisfied with the cancer primary prevention activities you currently develop?
- **6.** What are your main motivations for getting involved in cancer primary prevention activities?
- 7. Which barriers do you face when developing cancer primary prevention activities?
- 8. Which future activities would you like to develop?
- **9.** Are you familiar with the European Code Against Cancer? And if so, have you been involved in initiatives promoting the European Code Against Cancer?

#### C. PERCEPTIONS ABOUT OTHER STAKEHOLDERS

- We'd like to discuss the various stakeholders' sectors involved in cancer primary prevention, specifically focusing on the Governance/public sector, Academia and research, the Private sector, Media, and Civil society. [Share the slide with the sectors]
- **10.** For each sector, could you please tell us about the main differences in their activities and motivations? [Governance/Public sector | academia and research | private sector | media | civil society]
- **11.** Also, what do you see as the major barriers and opportunities for each sector in your country when it comes to cancer primary prevention?"
- **12.** Of all the mentioned sectors, in your opinion, which sector has the **main role in change** concerning cancer primary prevention in your country? Why?
- **13.** In your opinion, which sector is the **most proactive** in addressing cancer primary prevention in your country? Why?
- **14.** In your opinion, which sector is the **most influential** in addressing cancer primary prevention in your country? Why?

[In these questions, when the categorization by sector is not clear, "which sector" can be replaced by "which institution". If the participant is not able to identify "the main" or "the most", this can be replaced by asking for examples (e.g., "Can you tell me about an institution in your country that you consider proactive?]

#### D. INTERACTION BETWEEN STAKEHOLDERS

- **15.** With which main partners (institutional or individual) do you collaborate when you develop cancer primary prevention activities? [Here, it would be relevant to understand the activities of the partners, to make it possible to classify them in a sector]
  - O What is the main focus of that collaboration?
  - O What could be improved?
  - o Have you had bad experiences collaborating with other partners?
- **16.** How do you characterize the collaboration between sectors in your country?



- o Which entities best interact together to address CPP in your country?
- o What could be improved in the collaboration between entities?
- **17.** Finally, we would like to know if is there anything else you would like to add on this topic that you feel might be significant and not mentioned during the interview?

We have now finished our interview. Thank you very much for your collaboration.