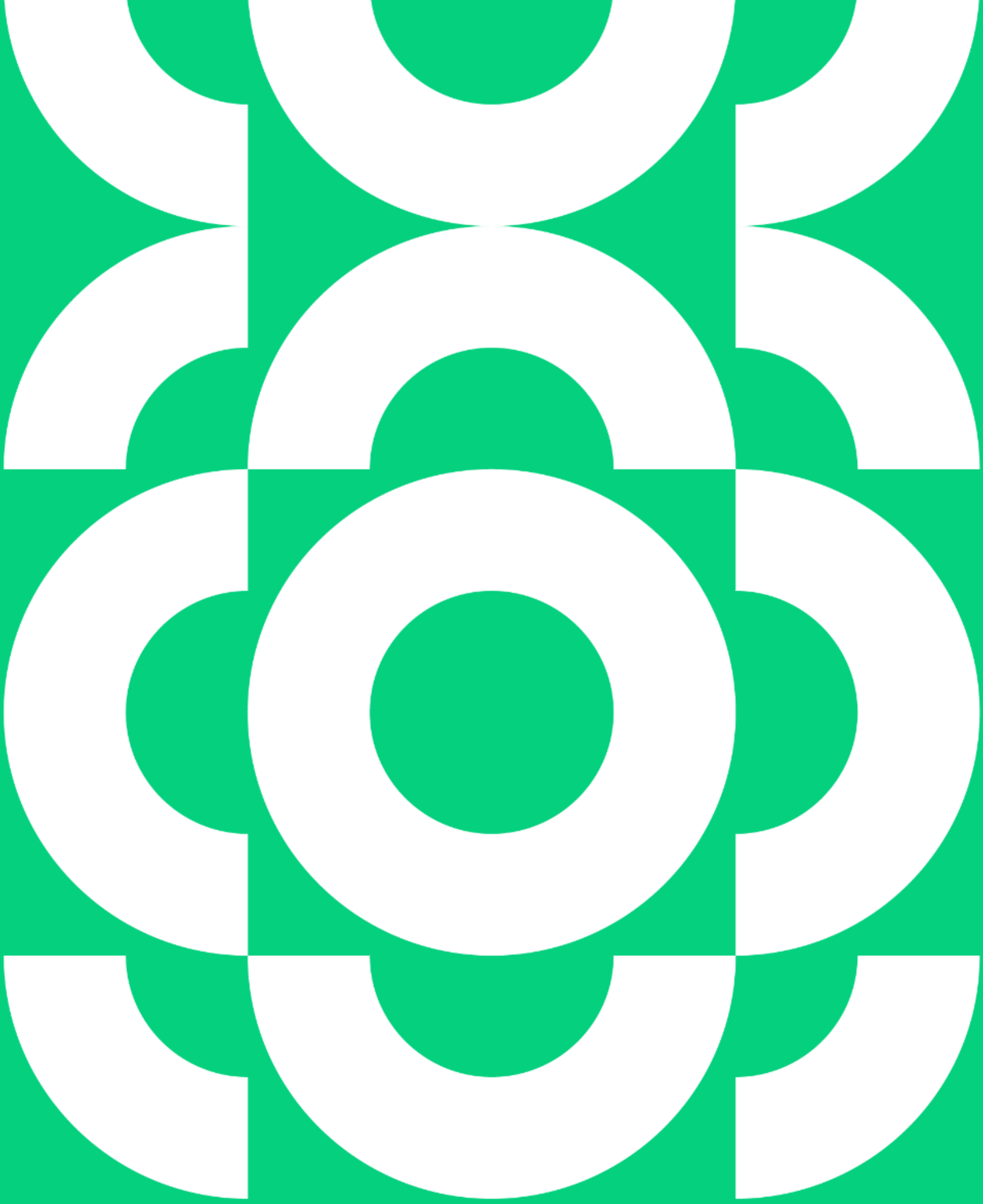

ECHoS
Cancer Mission Hubs

Landscape Analysis on Citizen Engagement

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Abbreviations

AICIB	Agência de Investigação Clínica e Inovação Biomédica – Delegação de Lisboa
AICRI	All-Island Cancer Research Institute (Ireland)
AYA	Amsterdam Young Academy
BMBF	Bundesministerium für Bildung und Forschung (Federal Ministry for Education and Research, Germany)
CCC	Comprehensive cancer centre
CSF	Cancer Society of Finland
DG	Directorate General
DKFZ	Deutsches Krebsforschungszentrum
DLR-PT	Deutsches Zentrum für Luft- und Raumfahrt – Projektträger
EC	European Commission
ECHoS	Establishing of Cancer Mission Hubs
EU	European Union
EUPATI	European Patients' Academy on Therapeutic Innovation
FICAN	National Cancer Center Finland
Fimea	Finnish Medicines Agency
FRRB	Fondazione Regionale per la Ricerca Biomedica (Italy)
G-BA	Gemeinsamer Bundesausschuss
GÖG	Gesundheit Österreich GmbH (Austrian National Public Health Institute)
HCP	Health Care Professional
HPV	Human papillomaviruses
HRCI	Health Research Charities Ireland
HSE-NCCP	Health Service Executive – National Cancer Control Programme
HTA	Health Technology Assessment
HUS	Helsinki University Hospital
iCAN	Digital Precision Cancer Medicine Flagship
Ignite	IGNITE UCC – Clár Gnó Iarchéime IGNITE (Ireland)
IKNL	Integraal Kankercentrum Nederland (Netherlands Comprehensive Cancer Organisation)
INCa	French National Cancer Institute
IPOSSI	Irish platform for patient organisations, science & industry
KETEM	Cancer Early Diagnosis Screening and Training Centre
KWF	Dutch Cancer Society
LBG	Ludwig Boltzmann Gesellschaft
MCST	Malta Council for Science and Technology
MS	Milestone
MSCI	M.Sklodowska-Curie National Institute of Oncology in Warsaw
NCCP	National Cancer Control Programme
NCMH	National Cancer Mission Hubs
NCT	Nationales Centrum für Tumorerkrankungen
NDK	National Decade Against Cancer
NFK	Netherlands Federation of Cancer Patient Organisations
NGO	Non-Governmental Organisation

OECD	Organisation for Economic Cooperation and Development
ÖKUSS	Österreichische Kompetenz- und Servicestelle für Selbsthilfe
PGO	Persoonlijke Gezondheidsomgeving
PPI Ignite	Public and patient involvement Ignite Network
Sfi	Swedish for immigrants
SGB	Sozialgesetzbuch
STEA	Funding Centre for Social Welfare and Health Organisations (Finland)
UCSC	Università Cattolica del Sacro Cuore Milano
UN	United Nations
WCD	World Cancer Day
WHO	World Health Organization
WP	Work package

Introduction

In its Alma-Ata declaration of 1978, the WHO emphasised that “the people have the right and duty to participate individually and collectively in the planning and implementation of their health care” (WHO, 1978), addressing the need and necessity for citizen engagement.

Since the 1970s, the concept of civic engagement has evolved into a means of good governance (OECD, 2022). Recently, the European Commission (EC) reaffirmed the importance of citizen engagement by advocating for active citizen engagement in public policy-making processes (EC, 2023).

Beyond implementing democratic decision making, citizen engagement also contributes to improving the quality of decisions by considering the perspectives of those who are affected by the decisions (Fung, 2006).[2] In the area of health (including cancer), citizen engagement is a good way to empower individuals in relation to their health and social needs, amplifying their voices and building capacity (Kale *et al*., 2023; WHO, 2023).

Citizen engagement can, therefore, be an objective in itself in terms of democratic decision making and a means to achieve a purpose, such as better decisions and the empowerment of those affected by such decisions. In recent years, supranational organisations such as the Organisation for Economic Co-operation and Development (OECD) and the World Health Organisation (WHO) have issued frameworks and guidelines to support citizen engagement in order to promote it (OECD, 2022; WHO, 2023). For example, the “WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions” (WHO, 2023) is intended to support WHO member states in meaningful engagement and to enhance related policies, programmes and services. On a structural level, citizen engagement can play a key role in shaping more inclusive and equitable cancer policies and solutions as well as in improving the quality of cancer care and education (cf. WHO, 2019). Citizen engagement is not only required in policy and practice but also in research.

Engaging citizens and patients in cancer research has been shown to be significantly beneficial in terms of improving cancer disparities (Leader *et al*., 2023). A study on enhancing citizen engagement in cancer screening via the method of deliberative democracy (Rychetnik *et al*., 2013), for example, suggested that when it comes to cancer screening policies, evidence-based recommendations by experts can be greatly enhanced by taking citizens' (informed) decisions into account as laypeople can help to evaluate questions regarding the practical implications of screening programmes. These include factors like the benefits and harms of screening, who screening should be provided to and how it should best be implemented. Overall, the authors of the study consider that citizen engagement via this participatory method increases the legitimacy and feasibility of policy decisions (Rytechnik *et al*., 2013).

In the context of the ECHoS project, citizen engagement serves a dual purpose: supporting the implementation of the EU Cancer Mission (EC, 2021) and adding value to the quality of cancer care. Citizens are not passive observers; they are active partners in defining the Mission's goals. Their lived experiences inform research priorities, resource allocation and innovative solutions.

In this light, the EU's Cancer Mission emphasises social engagement as a priority and recognises the role of citizens in shaping cancer policies and solutions (EC, 2018, 2021).

Despite the benefits of citizen engagement, implementing it is often challenging. It is becoming increasingly apparent that there is no single form of engagement. The culture and structure of the healthcare system in a particular country affect the implementation of citizen engagement. Countries with a longer tradition of citizen engagement can act as role models for countries that are just starting out. The ECHoS project aims the creation of National Structures – named National Cancer Mission Hubs – which primary goal is to ensure the implementation of Cancer Mission in their respective country. In this context, ECHoS aims to capacitate NCMHs in the methodology / framework of effective Citizen Engagement.

This landscape analysis aimed to collecting information on citizen engagement in cancer care across the 28 EU countries participating in the ECHoS project to better design training and capacity building activities in the area. Out of these 28 countries, 18 have responded to the survey by the end of the deadline and are therefore included in this report.

Purpose of this work

Milestone 13 (MS 13) is part of Task 6.2 in work package 6 (WP6) of the ECHoS Project. WP6 focuses on 'Communication, Dissemination, Citizens' Engagement & Participation'. MS 13 aims to collect information on the current state of play of citizen engagement on cancer among EU member states and associated countries within ECHoS. It was developed by the Austrian National Public Health Institute GÖG within the scope of Task 6.2 – 'Citizens' Engagement and Participation Activities'. A survey and subsequent analysis were employed to gain understanding of the current state of play regarding opportunities for citizen engagement in connection with cancer in Europe. A link to the online survey was sent to each ECHoS consortium partner to collect information on citizen engagement activities, methods, standard practices and more in each country. An overview of how the survey was constructed is given in the Conceptual framework and Methodology. The main findings from MS 13 will be displayed on the public ECHoS website.[3] Ultimately, the findings will help develop tools for citizen engagement to be used by existing and future National Cancer Mission Hubs (NCMHs) and, hence, aid the implementation of the EU's Cancer Mission in all participating countries.

The following sections of this report give an overview of the conceptual framework, methodology and results of the first 18 (of potentially 28) survey responses that were received by 3 April 2024 as well as a summary of the next planned steps in terms of visualising and publishing the results on the ECHoS website.

Conceptual framework

Definitions

One of the main challenges involved in successfully implementing citizen engagement lies in the diverse approaches associated with the concept of engagement (Forbat *et al*., 2009). Citizen engagement approaches can range from individual decisions (such as treatment choices) to collective decision-making processes at different levels (local, regional, hospital, health system). Additionally, these approaches commonly encompass different degrees of engagement, starting from preliminary stages such as information and extending to involvement in decision-making processes to achieving partnership (equal collaboration between citizens and decision makers).

This challenge is exacerbated in cross-country comparisons as it involves the collection of information on multiple different nations with their own distinct citizen engagement contexts and traditions. Therefore, the survey features a broad definition of "citizen engagement", allowing respondents to include comprehensive information on different levels and methods of citizen engagement within their national contexts.

Accordingly, the definition of "citizen" in the context of this work refers to residents of a given country, including (but not limited to) any individual affected by cancer, e.g. any person who is currently a cancer patient, a cancer survivor or is/has been a caregiver to or a relative of a cancer patient or survivor. "Engagement", in turn, refers to the possibility of influencing decisions taken in connection with different aspects of cancer. This can happen in various ways and settings as well as on several levels. Several examples of citizen engagement on various levels were also given in the introductory text to the survey (see more in Appendix).

Conceptual framework

The survey was designed based on a self-assessment tool for citizen participation[1], the C.L.E.A.R. framework (Council of Europe, 2006). This framework primarily aims at enhancing engagement at the local level and was also used as a basis for the ECHoS project stakeholder engagement activities in work package 3 (WP3). The C.L.E.A.R. framework is one of several tools, including guidelines and manuals, created by supranational organisations such as the WHO and the OECD (WHO, 2023; OECD, 2022) to enhance and support engagement activities. It stands for:

- Can do – resources and knowledge to participate;
- Like to – a sense of attachment that reinforces participation;
- Enabled to – provided with the opportunity for participation;
- Asked to – mobilised by official bodies or voluntary groups;
- Responded to – see evidence that their views have been considered.

The CLEAR framework can be used to assess the extent of engagement. It is not about a positive or negative assessment but meant as an aid to understanding what it takes for citizens to have the choice, capacity and opportunity to participate. The framework explicitly invites adaptation to the context concerned. This was also applied in the context of the survey addressed in this document.

Table 1 below summarises how the individual dimensions of the CLEAR[2] Framework were linked to the survey questions (for a detailed description see Methods). The 'like to' category was not explicitly included as a general assessment of this variable would require a large-scale survey of citizens' perceptions and is therefore not applicable in the context of this survey. Several open-ended answers relate to this category implicitly, however, as they highlight the importance of non-

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[1] Note that in this document, the terms "citizen engagement" and "participation" are used synonymously; in other words, we view participation as an element of citizen engagement and vice versa.

[2] Council of Europe 2008 – CLEAR: A self-assessment tool for citizen participation at the local level).

governmental organisations (NGOs) and patient organisations for patient participation.

Table 1 Overview of the CLEAR dimensions and their consideration in the questionnaire

Dimension	Questions/aspects in the questionnaire
Can do	» Communication channels, established engagement methods
Like to	» – not applicable –
Enabled to	» Provision of training and support, financial support (e.g. reimbursement of expenses for patient representatives)
Asked to	» Existence of regulations on who, where and when patient interests can be represented
Responded to	» Mechanisms for or transparency of how input from citizens/patients is taken up in the decision-making process. » Monitoring the impact of patient involvement

Methodology

The following steps were employed to achieve this milestone:

1) Survey design and feedback loop/testing by WP6 members:

In a first step, the GÖG team developed an initial draft, loosely based on the CLEAR framework as mentioned above. In October 2023, the draft was shared with WP6 members for their feedback. After it had been implemented, in December 2023, a link was shared with members of WP6 and WP1 with the invitation to test a pilot version of the survey distributed as a PDF.

It consisted of five sections:

- Communication – aiming to include comprehensive information on several aspects related to the most basic/primary level of engagement (related to the “Can do” dimension of the CLEAR framework);
- Opportunities and methods – aiming to gain an overview of the current available opportunities for citizen engagement in each country (also related to the “enabled to” dimension of the CLEAR framework);
- Training and education – aiming to acquire an understanding of the availability of enabling factors to enhance citizen engagement (“enabled to” of the CLEAR framework);
- Processes, regulations and policy aspects – aiming to gain a comprehensive understanding on various aspects related to the “Asked to” and “Responded to” dimensions of the CLEAR framework (for each dimension and its elements see Table 1 of the conceptual framework);
- A final and fifth section, extending beyond the CLEAR framework, covered “recommendations” and provided the opportunity to collect a wide range of recommendations from different national contexts, which will facilitate knowledge exchange at a later stage.

2) LimeSurvey/adapting survey features:

Once the feedback on the draft survey was incorporated, the survey was imported into LimeSurvey (January 2024) in order to facilitate its dissemination across the 28 participating countries.

The survey was then discussed by the Executive Board, after which it was presented to members of the Strategic Advisory Board in the January 2024. The survey was then adapted to incorporate all inputs provided by both EB and STAB members and shared for final revision. A definitive version was completed and distributed in February 2024. The final survey is available in the Appendix and includes a mix between multiple choice questions (each answer option with corresponding textbox to include links or comments) and open-end questions.

3) Data collection process:

A qualitative and centralised/coordinated approach was employed for data collection. This approach involved assigning one contact person per participating country responsible for organising a meeting or written input from various stakeholders on a national level.

February 2024:

- In a first step, as mentioned above, the survey was sent to all participating beneficiary consortium members, which were contacted by a GÖG team member by email. It also included guidelines on options for gathering information with national experts with expertise in different relevant areas of citizen engagement and/or cancer care.
- Each member state partner was asked to provide **one** consolidated response per country when filling out the online survey. Partners were encouraged to consult with their national hub-like structures. Respondents were also provided with a PDF version of the survey (see Appendix) in order to facilitate the gathering of information with a range of stakeholders.
- The initial deadline was set as 18 March 2024 and was then extended to 3 April. Upon several requests by partners – needing more time to be able to collect information via workshops or bilateral meetings.

April 2024:

- A response rate of 18 out of 28 countries was achieved by 3 April 2024, also with the support of members of the coordination team (WP1), who sent a reminder email one week before the deadline. The following countries were therefore included in the analysis for this report: Austria (AT), Czech

Republic (CZ), Germany (DE), Estonia (EE), Finland (FI), France (FR), Croatia (HR), Ireland (IE), Italy (IT), Luxembourg (LU), Latvia (LV), Malta (MT), the Netherlands (NL), Norway (NO), Poland (PL), Portugal (PT), Sweden (SE), Slovakia (SK) and Türkiye (TR).

- Responses from any remaining countries will be considered and analysed at a later stage. Parts of the information from the report will subsequently be included on the website in the form of short summaries (per country) within each category.
- A response of 64% (18 / 28 countries) was achieved as a combined result from extended deadline and reinforced reminder E-mail one week before the deadline. The following countries were therefore included in the analysis for this report: (AT, CZ, DE, FI, FR, HR, IE, IT, LU, LV, MT, NL, NO, PL, PT, SE, SK, TR)

Next Steps:

Responses from any remaining countries will be considered and analysed at a later stage. Parts of the information from the report will subsequently be included on the website[3] in the form of short summaries (per country) within each category.

Table 2: Overview of stakeholders included per country.

Processes and stakeholders included per country			
Country	First respondent	Other stakeholders included	Type of process
Austria	National Public Health Institute (GÖG)	» Ministry of Health » Academic or research Institution » Civil society	Meeting / workshop

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[3] https://cancermissionhubs.eu, accessed 22 April 2024

		organisation » Patient organisation » Cancer centre » Pharmaceutical industry	
Croatia	Koalicija udruga u zdravstvu (Coalition of Associations in Healthcare)	» Patient organisation	Based on communication with member associations
Czech Republic	Institute of Haematology and Blood Transfusion	» Not provided	Collecting written answers, calls
Estonia	Tartu University Hospital	Cancer centre	Meeting
Finland	Helsinki University Hospital (HUS) / National Cancer Center Finland (FICAN)	Cancer Society of Finland	Collecting information from partners and websites
France	French National Cancer Institute (INCa)		Collecting answers from colleagues at the "Living Lab & Health Democracy" Mission within the French National Cancer Institute
Germany	Federal Ministry for Education and Research (BMBF)	Not provided	Internal feedback loops between DLR-PT colleagues and the BMBF
Ireland	HSE-NCCP and AICRI	Other	Collecting written answers from members of the National Cancer Research Group

Italy	INT, UCSC, FRRB, FDB, FTB	Academic or research institution	Meeting
Latvia	Riga East University Hospital	Patient organisation	Meeting
Luxembourg	Institut National du Cancer (INC)	Academic or research institution	Meetings
Malta	Ministry for Health and Active Ageing	Academic or research institution	Consultation with the Malta Council for Science and Technology
Netherlands	Netherlands Comprehensive Cancer Organisation (IKNL)	Patient organisation	Searching policy documents and a web search, combined with knowledge from the IKNL and partners
Norway	Norwegian Cancer Society	Other	Meeting with key mission hub partners
Poland	M.Sklodowska-Curie National Institute of Oncology in Warsaw (MSCI)	Ministry of Health, National Health Institute, Patient Organisations, Cancer Centers, Academic or Research Institution	Meeting
Portugal	Agency for Clinical Research and Biomedical Innovation (AICIB)	Other	Multiple meetings and collecting written answers
Slovakia	National Oncology Institute	Other	Collecting written answers in the editable pdf survey prepared for this purpose and by daily working experience

Sweden	National Board of Health and Welfare coordinating on behalf of certified comprehensive cancer centres (CCCs) and the six regional cancer centres	Cancer centre	Written answers, collective input
Türkiye	Health Institutes of Turkey	Public health institute	Collecting written answers

1. **Data analysis:** Answers were exported the answers from the 18 respondent countries from LimeSurvey into excel and developed a list of indicators per category and sub-categories (reflecting each question). Comments and written text regarding good practice opportunities and methods were summarised using a basic content analysis method (an inductive approach as a thematic analysis) to identify similarities and differences across countries and categories. The results were then summarised in the results section of this report (see Results). The results were first summarised per category. The replies represent / are based on the views and understanding of the respondent(s), and there may be some information (or methods, communication channels, stakeholders, etc) missing from the landscape analysis. In a subsequent stage, more detailed country profiles will be developed and published on the ECHoS website[4] in June 2024)

2. **Validation of data:** Within the group of questions about training, some respondents gave examples unrelated to the topic, for example the availability of “health education” as well as training and information materials on the topic of cancer for citizens. This represents a limitation in terms of adequately representing the results as it acts as a confounding factor. Therefore, in these cases, we did not include the

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[4] https://cancermissionhubs.eu, accessed 22 April 2024

responses in the category concerned in the empirical/numerical table of results.

Results

Citizen engagement on cancer across EU countries: a comprehensive overview of the results

This section presents the aggregated summaries of key results of the survey. These summaries encapsulate the most significant findings within each category, providing a comprehensive overview of the outcomes of the survey.

Methods and opportunities

Opportunities/initiatives/activities for citizen engagement

Answers to the open-ended question about what types of opportunities/initiatives/activities exist for citizen engagement that are related to cancer illustrate the breadth and levels of engagement as well as the possible interpretations of the question on engagement activities. In some countries, the focus is on promoting individual engagement in cancer prevention, screening and treatment through awareness-raising measures such as information campaigns and events (e.g. Prague Marathon – Runners for Cancer Warriors in the **Czech Republic**). Other opportunities relate to information and exchange regarding activities and decisions in the healthcare system: one country (**Croatia**) reported that national policy documents are also published. In several countries there are cancer-specific events where (in some cases) a focus is also placed on patient engagement (e.g. the German Cancer Congress). Consultative participation opportunities are mostly reported in the context of patient engagement; only once is a public consultation (= public/citizens engagement) mentioned involving cancer-related strategy documents (e.g. the national Cancer Plan) in **Malta**. Patient involvement activities, in contrast, were quite common, e.g. involvement in research projects or in the selection of research projects (**Germany**), involvement in hospital-related (e.g. **Finland, Latvia**) or national committees (**Germany**). Several countries also report on the activities of patient organisations and/or NGOs that organise activities. A few countries mentioned training for patient organisations and financial support for patient organisations (**Germany**, **Slovakia**). **Norway** was the only country to report that there are general participation opportunities that are not specific to health/cancer but that can also include participation in this area.

Methods used for citizen engagement on cancer

The close-ended question about engagement methods (see Figure 1) also illustrates the prevalence of participation in research projects (n=15, 83%) and consultations (n=15, 83%). More than half of the countries reported community workshops and forums (n=13; 72%) as well as online platforms and surveys (n=10, 56%). Fewer than half of the countries mentioned patient advisory boards (n=8, 44%) or citizens' councils (n=3, 17%). Individual countries stood out positively with the implementation of five (**Austria**, **France**, **Germany**, **Netherlands**, **Norway**, **Slovakia**) or four (**Ireland**, **Sweden**) engagement methods. Five countries reported on three engagement methods and five on only two.

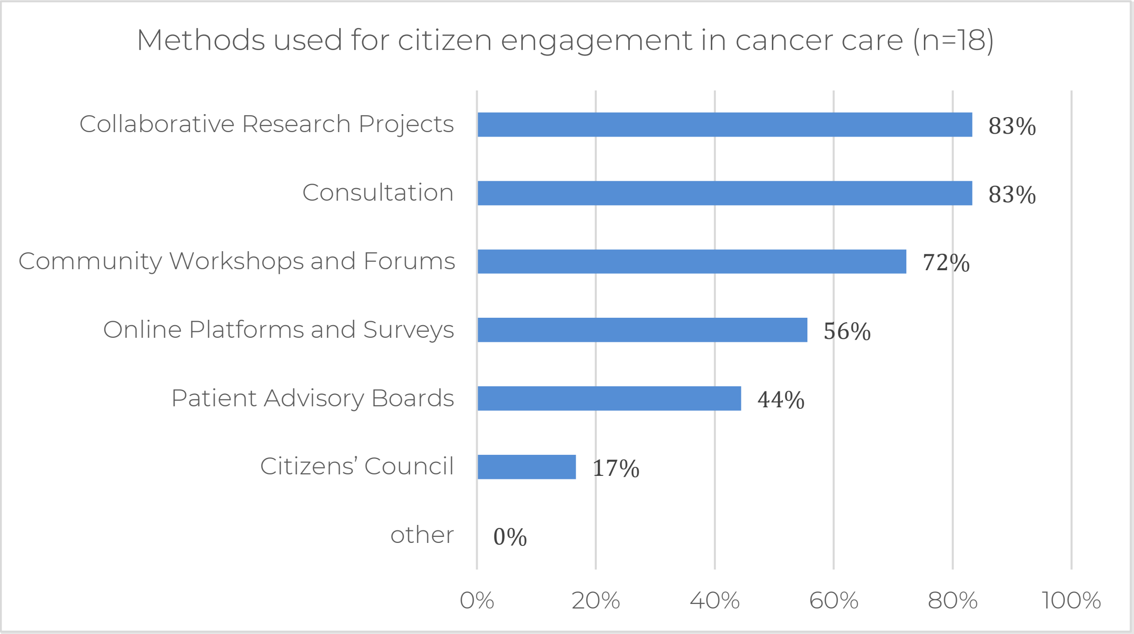

Figure 1: What methods are used for citizen engagement in cancer in your country?

Table 3 : Answers for "opportunities and methods" (1=yes, 0=no)

Question	Multiple choice options	AT	CZ	DE	EE	FI	FR	HR	IE	IT	LU	LV	MT	NL	NO	PL	PT	SE	SK	TR
Methods used for citizen engagement in cancer care in the given country	Citizens' Councils	1	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	0	0	0
	Consultation	1	0	1	0	1	1	0	1	1	1	1	1	1	1	1	1	1	1	0
	Patient Advisory Boards	1	0	1	0	1	1	0	1	0	0	0	0	1	1	0	0	0	1	0
	Community Workshops and Forums	0	1	1	1	0	1	0	1	1	1	0	1	1	1	1	0	1	1	0
	Online Platforms and Surveys	1	1	1	0	0	1	1	0	0	0	0	0	1	1	0	0	1	1	1
	Collaborative Research Projects	1	0	1	1	1	1	1	1	1	1	0	0	1	1	0	1	1	1	1
	Other	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Sum	4	2	5	2	3	5	3	4	3	3	1	2	5	5	3	2	4	5	2

Information and communication

The participating countries were asked to indicate which methods they use to provide information on citizen engagement (see). All countries reported on the use or existence of social media and online platforms and 17 mentioned public health websites and portals. More than two-thirds also reported on the use of information channels via health care providers and clinics (n=15, 83%) as well as patient support organisations (n=15, 83%) and community events and workshops (n=13, 72%). Less frequently, but still covering more than half of the countries, the existence of other information channels such as printed materials and brochures (n=10, 56%), government campaigns (n=10, 56%); local news and media (n=10; 56%) and educational institutions and schools (n=11, 61%). Seven countries wrote that they used all of the nine information channels surveyed (**Germany, Estonia, Croatia, Latvia, Poland, Slovakia** and **Türkiye**). Three countries (**Austria**, the **Netherlands** and **Sweden**) made use of seven information channels, two countries used five (**Czech Republic**, **Norway**) and six mentioned three to four information channels. The median number of channels per country was 7.

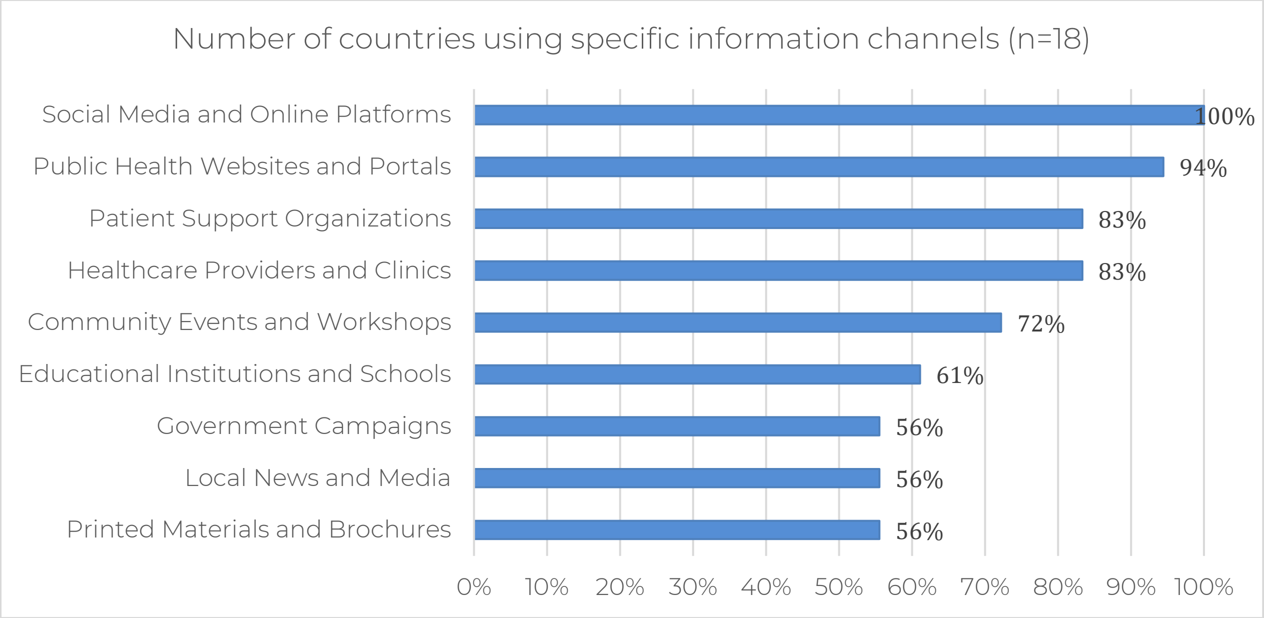

Figure 2: Please describe via which channels information regarding opportunities/activities for citizen engagement on cancer is communicated to citizens in your country.

The accessibility and comprehensibility of communication was most frequently rated as “Generally clear and accessible, but there might be room for improvement in certain areas” (n=10, 56%). Two countries rated it as “Highly accessible to all” (**Slovakia** and **Türkiye**). Four countries reported that there was significant room for improvement. It should be noted that three countries (**Ireland**, **Poland** and **Slovakia**) submitted several estimates.

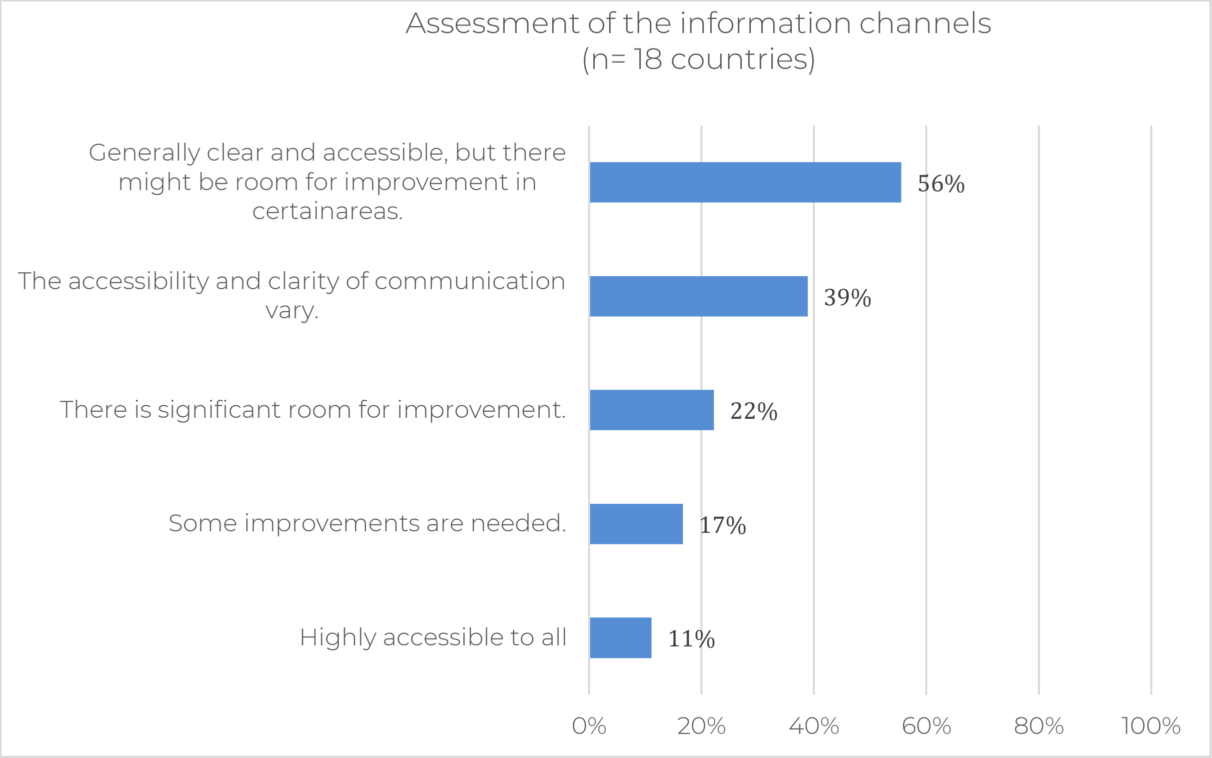

Figure 3: Do you consider communication strategies, plans and materials regarding citizen engagement on health and/or specifically cancer to be easily understandable and accessible to the wider public?

Table 4: Answers for "Communication" (1=yes, 0=no)

Question	Multiple choice options	AT	CZ	DE	EE	FI	FR	HR	IE	IT	LU	LV	MT	NO	NL	PL	PT	SE	SK	TR
Information channels regarding opportunities/activities for citizen engagement on cancer	Public Health Websites and Portals	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1	1	1	1	1
	Healthcare Providers and Clinics	1	1	1	1	1	1	1	0	1	0	1	1	1	1	1	0	0	1	1
	Community Events and Workshops	1	1	1	1	0	1	1	0	0	1	1	0	0	1	1	0	1	1	1
	Social media and Online Platforms	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1
	Printed Materials and Brochures	1	0	1	1	0	0	1	0	0	0	1	0	0	1	1	0	1	1	1
	Local News and Media	0	0	1	1	0	0	1	0	0	0	1	0	1	1	1	0	1	1	1
	Patient Support Organisations	1	1	1	1	1	1	1	0	0	0	1	1	1	1	1	0	1	1	1
	Government Campaigns	0	0	1	1	0	0	1	1	1	0	1	1	0	0	1	0	0	1	1
	Educational Institutions and Schools	1	0	1	1	0	0	1	1	0	1	1	0	0	0	1	0	1	1	1
	Sum	7	5	9	9	3	4	9	4	4	4	9	4	5	7	9	2	7	9	9

Training

This section describes findings related to 1) training programmes and/or training information materials on the topic of citizen engagement for the general public and 2) training programmes and information materials for healthcare professionals.

Findings on training programmes/materials for the general public:

Data from the first 18 countries to respond reveal that the majority of these countries have at least one form of training material related to citizen engagement, designed for a broad public audience, including individuals, civil society organisations and patient advocacy groups. Out of the 18 countries, six (33%) indicated the existence of educational programmes and twelve (67%) reported on the availability of educational materials on citizen engagement specifically related to cancer (see Figure 4). A detailed list of responses specific to each country can be found in Table 4 below.

The types of answers ranged from training programmes aimed specifically at how to inform and involve migrant groups and migrant cancer patients (such as in the **Netherlands**) to awareness-enhancing programmes targeting the prevention, early diagnosis and treatability of cancer organised for the general public, such as in **Türkiye.** These types of programmes are commonly organised by health ministries, local governments, civil society organisations and healthcare institutions. Moreover, the **Netherlands** indicated the existence of training programmes for health professionals about how to involve patients, many of which are developed during research projects (for more information see the country profiles).[5] The **Croatian** experts indicated that educational materials exist which are developed by patient organisations and commonly include the education of

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[5] In this context, the respondents from Germany mentioned a recent publication on the involvement of patient representatives from 2023 (in German only): https://zenodo.org/records/7908077

patients and caregivers as well as education on policy in healthcare including different patient empowerment programmes.

Three countries, **Germany**, **Finland, Portugal** and **Austria**, mentioned 'The European Patients' Academy on Therapeutic Innovation' (EUPATI) training courses offered in their countries. Furthermore, ÖKUSS, the **Austrian** Competence and Service Centre for Self-Help, has the task of supporting nationwide self-help organisations and strengthening patient participation. Specifically, ÖKUSS organises further training opportunities for nationwide self-help organisations and publishes guidelines/orientation aids for those responsible for committees. It is currently working on guiding principles for committee work. In **Germany**, these courses are aimed at industry representatives and researchers while EUPATI **Finland** has training activities that are open to all patients or interested stakeholders regardless of disease type (https://fi.eupati.eu/). In **Finland**, the Medicines Agency (Fimea) also has a patient advisory board for patient organisation representatives to inform and engage civil society and patient representatives. In **Austria**, general training materials produced by EUPATI are commonly used, as are some cancer-specific education materials such as webinars created by the Vienna Tumour Congress. Further training opportunities for oncology patient organisations are in development. Other general training is offered by various organisation such as the LBG Open Innovation in Science (general training and educational materials/webinars).

Luxembourg stated to hold general training for the general public to explain the concept and relevance of public and patient involvement (PPI) and how patients and the general public can be involved in different steps of research. Similarly, **Poland** indicated that there was training for PPI on a national level (e.g. Ignite and IPOSSI). Here, information material on citizen engagement is commonly generated by multiple agencies, including the Health Service Executive and cancer charities. Some charities even run their own educational and training programmes for interested citizens impacted by cancer.

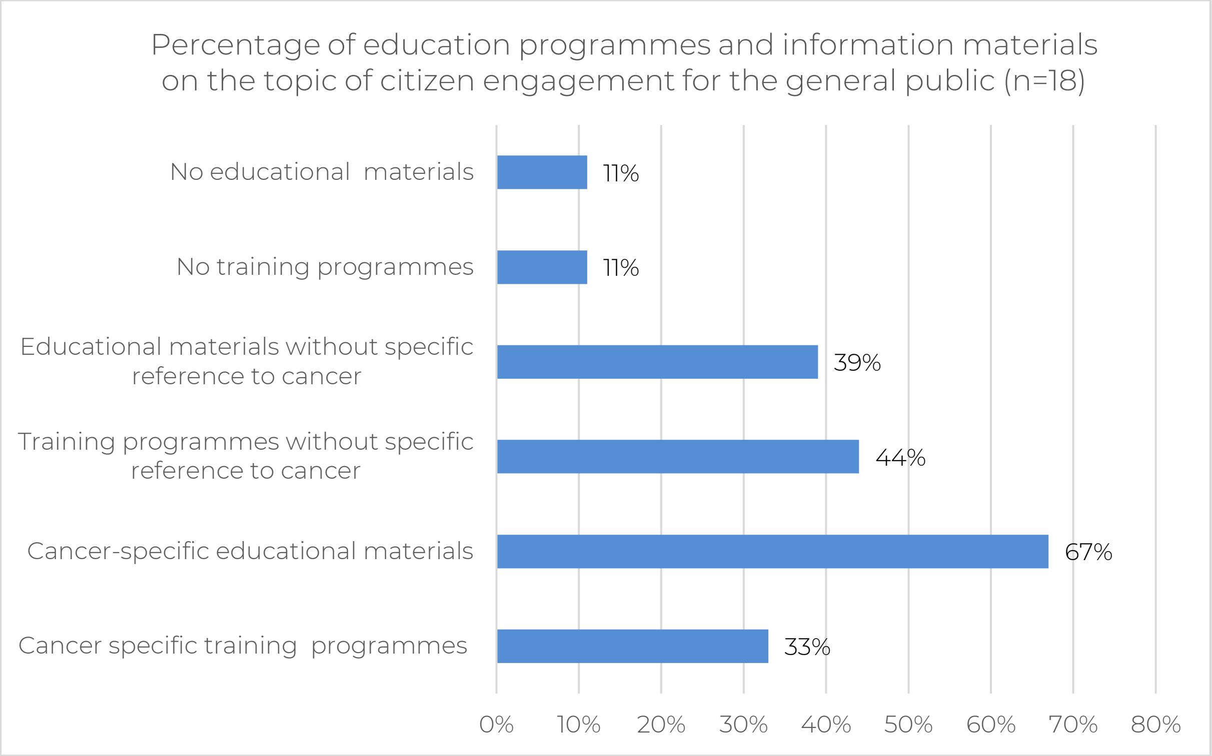

*Figure 4: Responses on the availability of training and education materials for the general public. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once. Please note that the "other" option was removed as it was chosen by 0% of the respondents.*

Findings on training programmes and/or training information materials on the topic of citizen engagement for healthcare professionals:

In the realm of healthcare professionals, the survey results indicate a diverse range of educational materials, with 33% of the respondents reporting the availability of materials both with and without specific reference to cancer. Furthermore, 22% highlighted the existence of training programmes related to citizen engagement on cancer while 17% indicated the presence of cancer-specific training programmes in their countries. Interestingly, only 11% of respondents, meaning 2 out of the 18 countries, reported a lack of educational materials. Similarly, a mere 3 countries (17%) reported the absence of current training programmes (see Figure 5).

In **Sweden**, the national authorities are working together to establish guidelines for patient and citizen interaction, which includes information exchange, dialogue and co-creation, along with providing recommendations for financial reimbursement. Similar guidelines are also provided by regional cancer centres and several healthcare regions. Moving to the **Netherlands,** there are training programmes available for professionals to enhance patient involvement and participation, although these programmes are not cancer specific. Additionally, an organisation called ‘Participatiekompas’ offers training for professionals and provides leaflets, web-based information and advice. **Austria** also refers to some educational materials for healthcare professionals without specific reference to cancer such as guidelines for committee chairs (by ÖKUSS) and a series of materials on patient advocacy created by the organisation ‘Kurvenkratzer’. In the realm of cancer-specific competency training for citizen and patient engagement, the Austrian platform for health competency offers training materials on conversation training for healthcare professionals. Similarly, in **France**, the “Université des Patients” initiative offers programmes for representatives of the healthcare system. While the **Czech Republic** has numerous specific programmes running within different institutions and departments, there is no systematic reporting or evidence of these. In contrast, in **Türkiye**, all in-service training for cancer includes programmes that are organised around awareness, public information and the importance of health literacy, and they utilise relevant educational materials.

These examples from different countries provide a glimpse into the diverse approaches to citizen engagement in healthcare across the surveyed countries. Upon closer analysis of the comment section for this group of questions, it becomes apparent that the programmes and materials offered are often more specific to "patient engagement"; in other words, the examples described in the comment section mostly relate to programmes and materials aimed at patients (rather than the general public).

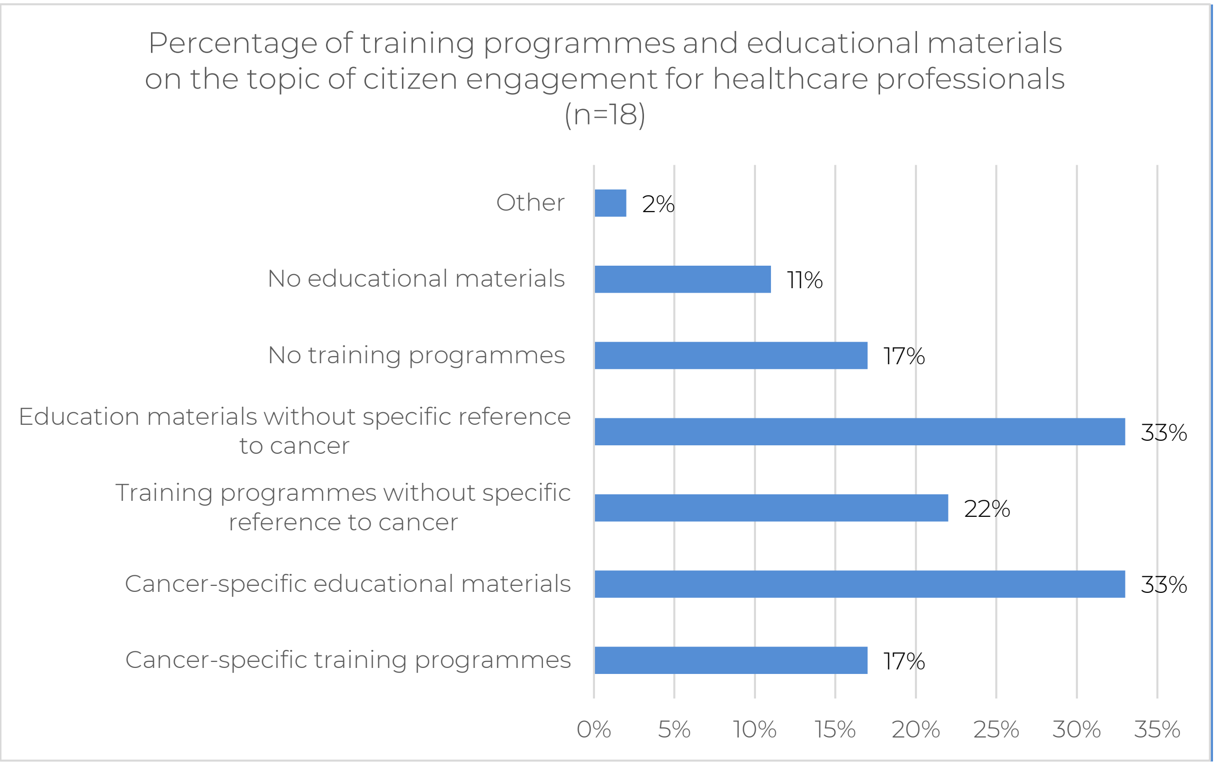

*Figure 5: Responses on the availability of training programmes and educational materials for healthcare professionals. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

Table 5: Answers for "Training and education" (1=yes, 0=no)

Question	Multiple choice options	AT	CZ	DE	EE	FI	FR	HR	IE	IT	LU	LV	MT	NL	NO	PL	PT	SE	SK	TR
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy?	Cancer-specific training programmes	1	0	0	0	0	1	1	1	0	0	0	0	1	0	0	0	0	1	0
	Cancer-specific educational materials	1	0	1	1	0	1	1	1	0	0	0	1	1	1	1	0	1	1	0
	Training programmes without specific reference to cancer	0	0	1	0	1	0	1	0	0	1	0	0	1	1	0	1	1	0	0
	Education materials without specific reference to cancer	1	0	1	0	0	0	1	0	0	0	0	1	1	1	0	1	0	0	0
	No training programmes	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
	No educational materials	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
	Comment provided	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	Cancer-specific training programmes	0	1	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0
	Cancer-specific education materials	1	0	0	0	0	1	1	1	0	0	0	0	1	0	1	0	0	0	0
	General training programmes without specific reference to cancer	0	0	0	1	0	0	0	0	0	0	0	0	1	1	0	1	0	0	0
	Educational materials without specific reference to cancer	1	0	0	0	1	0	0	0	0	0	0	0	1	1	0	1	1	0	0
	No training programmes	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	1	0
	No educational materials	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1	0
	Other was ticked	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Processes, regulations and policy aspects

The fourth overarching dimension in the survey relates to “Processes, regulations and policy aspects” and includes the following five sub-categories: 1) regulations, 2) funding incentives, 3) good practices, 4) transparency and 5) monitoring.

Regulations

The survey posed two questions pertaining to regulation. The first question sought to determine whether, at a national level, regulatory frameworks are in place in the health sector to define who can officially and legally represent citizens’ interests. As depicted in Figure 6 below, 8 out of the initial 18 respondents (44%) indicated the existence of legally binding references in their country while 39% reported the absence of such regulations. Furthermore, 33% of respondents indicated the presence of unspecific references regarding who may represent citizens’ interests while 33% indicated “other”. Table 6 below shows the specific replies per country regarding both questions on regulation.

Regarding legally binding regulations, in **Germany**, a distinction is made between informal and formal citizen participation. The respondents stated that for topics and issues concerning the National Decade Against Cancer, only informal citizen participation can be assumed, for which there is no legal regulation. However, for the measures of the Federal Joint Committee (G-BA), legal regulations are set out in §140f SGB V and §140f SGB V, respectively. In the **Netherlands**, all healthcare providers are legally obliged to maintain a Patient Advisory Board that is made up of patients, survivors, relatives and/or healthy citizens. **Norwegian** respondents referred to “user participation in health” where users have the right to participate in health and healthcare institutions have a duty to involve users. User participation in Norway is a statutory task and provides patients and next of kin with the opportunity to influence the design of health services. In **Croatia**, the legal framework in healthcare describes and determines the involvement of different stakeholders in healthcare in general, not specific to cancer. In **Poland**, patient organisations may be authorised to represent the interests of a citizen or patient in the field of health, as set out in the Act of 6 November 2008 on Patients’ Rights and the Patients’ Ombudsman. **France** has national associations of users of the healthcare system regulated under Article L. 1114-1 of the French Public Health

Code. **Portugal** has several different laws (such as Portaria n.º 535/2009) that regulate the process of recognising the scope and representativeness, the registration and forms of support of associations defending health users. This is subsequently maintained by the DG-Health. Similarly to Norway, Portugal also has a Charter for Public Participation in Health and legislation on the rights and duties of the users of health services.

In relation to unspecific references, the **Netherlands** indicated large funds for scientific research that maintain a robust policy for patient participation, as drawn up by the Dutch Cancer Society, for example. In the **Czech Republic**, patients can be represented through patient organisations, which operate under clear rules regarding their formation and function and play a clear role in some legislative processes. **Ireland**'s National Cancer Strategy refers to who can represent citizens but only as part of the Cancer Patient Advisory Committee. In **France**, most regulatory frameworks are internal guidelines or procedures specific to each institution; hence terminology may vary.

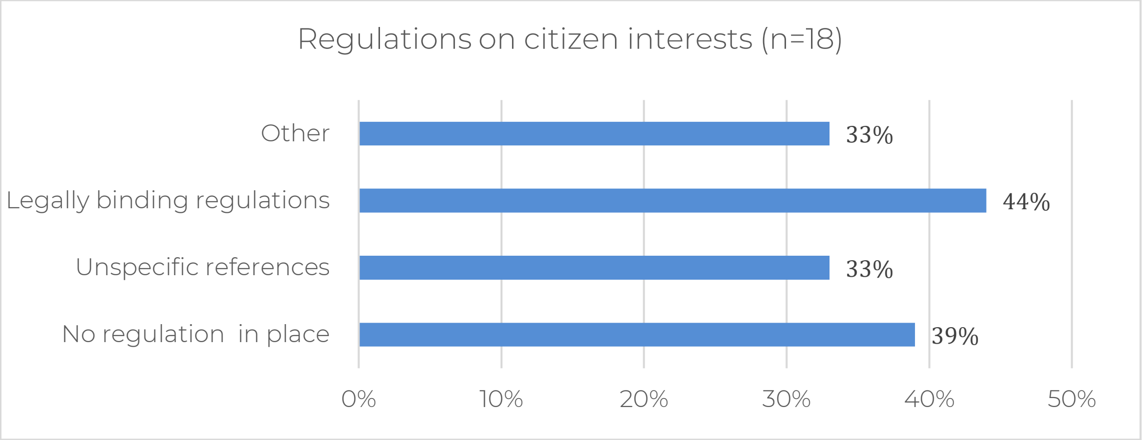

*Figure 6: Responses regarding the regulatory framework on who may represent citizens' interests. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

In the second question pertaining to regulations, participants were asked to identify whether their countries have regulatory frameworks that delineate how and where citizens can participate in cancer-related engagement activities, such as committees and consultations. Just over a quarter (28%) indicated the presence of legally binding regulations while 39% reported the existence of unspecific references. A further 22% responded with “other” and 39% of respondents indicated a complete absence of any such regulations (see Figure 7 below).

With regard to unspecific references, **Norway** reported that consultations are frequently conducted with patient organisations rather than by directly engaging citizens. These organisations are selected as relevant bodies, which are consultated among other organisations and institutions. In the **Netherlands**, a representative of the Netherlands Federation of Cancer Patient Organisations (NFK) is a full member of the National Oncology Taskforce. In policy and research projects, there is often a preference for a patient representing a patient organisation to participate. The NFK, which has 21 allied cancer patient organisations, can often send a representative to participate in policy discussions. The **Czech Republic** reported that their Ministry of Health has published rules and guidelines for patient organisations, including those related to cancer, for organisations wishing to be included on the ministry’s website. **France** reported that most of their regulatory frameworks are in the form of internal guidelines or procedures specific to each institution, leading to variations in terminology. In terms of legally binding regulations, as for the question above, France referred to the National Associations of Users of the healthcare system, which are regulated under Article L. 1114-1 of the French Public Health Code. The **Portuguese** respondents reported that there is no general regulation defining how and where citizens can participate in cancer-related engagement activities. However, some activities, such as those promoted by the regulatory agency for Medicines and Health Technology Assessment, have their own specific regulations.

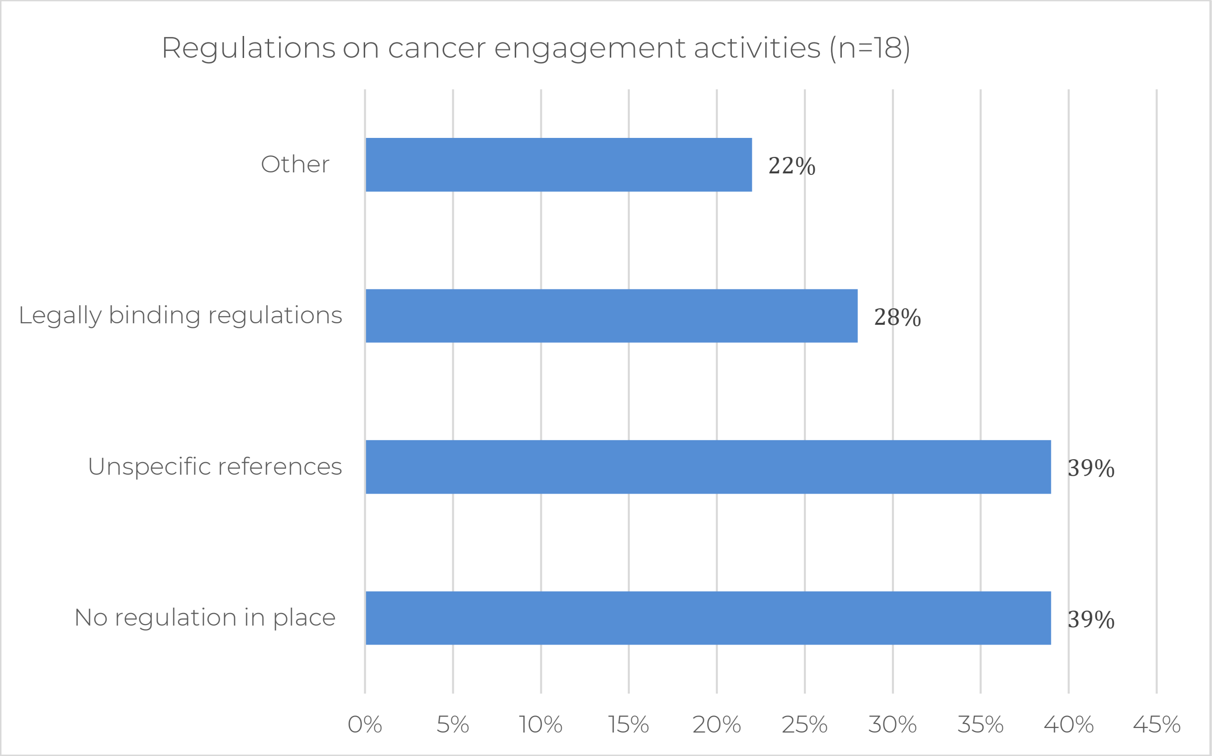

*Figure 7. Responses on the regulatory framework concerning citizen engagement on cancer. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

Table 6: A. Answers for "Processes, regulations and policy aspects" (1=yes, 0=no)

Question	Multiple choice options	AT	CZ	DE	EE	FI	FR	HR	IE	IT	LU	LV	MT	NO	NL	PL	PT	SE	SK	TR
Regulations on citizens' interests	No regulation in place	1	0	0	1	1	0	0	1	0	1	1	1	0	0	0	0	0	1	0
	Unspecific references	0	1	0	1	0	1	0	1	0	0	0	0	0	1	0	0	0	0	0
	Legally binding regulations	0	0	1	0	0	1	1	0	0	0	0	0	1	1	1	1	0	0	1
	Other was ticked	0	0	0	0	0	1	0	1	1	0	0	0	0	0	1	0	1	1	0
Regulations on cancer engagement activities	No regulation in place – it is not formally defined who can represent citizens	1	0	1	0	1	0	0	1	0	1	1	1	0	0	0	0	0	1	0
	Unspecific references	0	1	0	0	0	1	0	0	0	0	0	0	1	1	0	0	1	1	0
	Legally binding regulations	0	0	0	0	0	1	1	0	0	0	0	0	0	1	1	0	0	0	1
	Other was ticked	0	0	0	1	0	0	0	1	1	0	0	0	0	0	0	1	0	0	0
Funding incentives	Direct funding to support individual citizens	0	0	0	0	0	1	0	1	1	0	0	0	0	1	1	0	0	1	0
	Funding for patient organisations	0	0	1	1	1	1	1	0	1	0	0	0	0	1	1	0	1	1	1
	Other was ticked	1	1	0	0	0	0	0	1	0	1	1	1	1	0	0	1	0	0	0

Table 6: B. Answers for “Processes, regulations and policy aspects” (continued) (1=yes, 0=no)

Question	Multiple choice options	AT	CZ	DE	EE	FI	FR	HR	IE	IT	LU	LV	MT	NO	NL	PL	PT	SE	SK	TR
Transparency	Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	1	0	0
	Public input/consultations/opinions on a law regarding proposed laws are made publicly visible	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0
	There is accessible information on whether public input was considered in decision-making process	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	1	0
	There are platforms for public feedback, such as websites that allow for online public feedback	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	1	0
	No mechanisms	1	1	0	1	1	0	0	0	0	1	1	1	0	1	0	1	0	0	1
	Other was ticked	0	0	1	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0
Monitoring	Yes	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
	No	1	1	0	1	0	1	1	0	0	1	1	1	0	1	0	1	0	1	1
	Other was ticked	0	0	0	0	1	1	0	0	1	0	0	0	0	0	1	0	1	0	0

Funding initiatives

In the second part of the question group on processes, regulations and policy aspects, a question on funding incentives asked whether respondents were aware of any funding incentives to support citizen engagement activities related to cancer in their country. As Figure 8 below indicates, 61% of the participating countries responded that funding was available for patient organisations in their country. Another 33% indicated that there was direct funding to support individual citizens for citizen engagement related activities. Finally, 44% chose the "other" option.

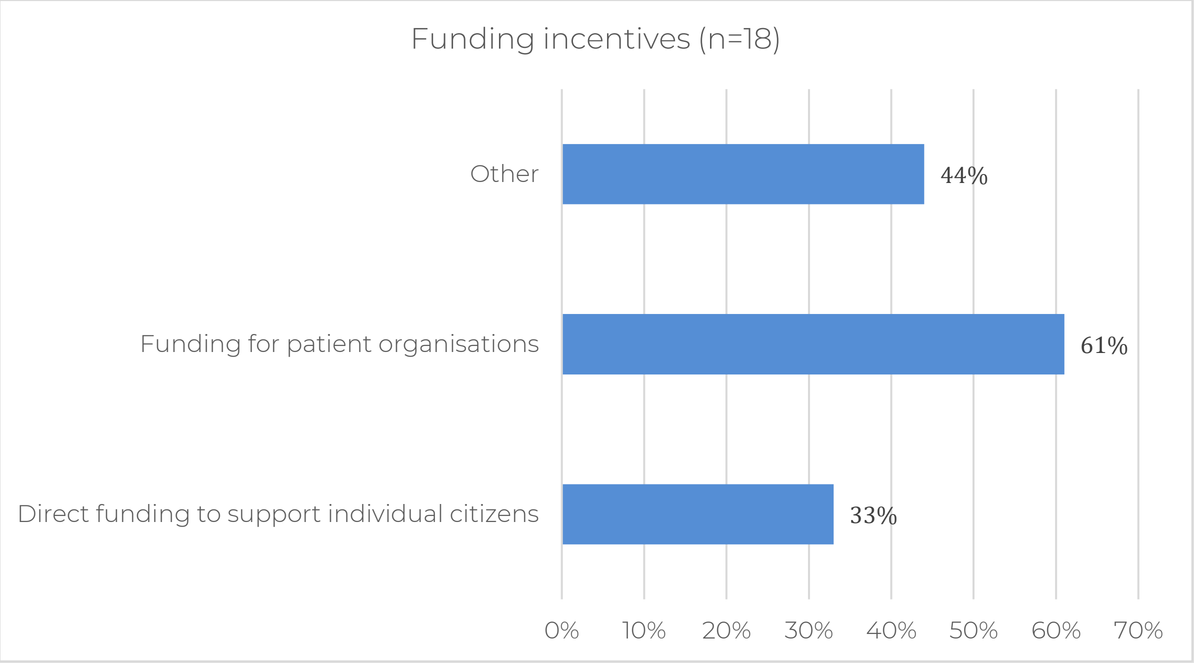

*Figure 8. Funding incentives. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

In the **Netherlands**, patients involved in research projects and patient advisory boards can receive reimbursements for travel and sometimes financial incentives, funded by the healthcare organisation. Similarly, patient organisations in the Netherlands receive funding from both the Dutch Cancer Society and the Ministry of Health. In **Germany**, the BMBF encourages patient involvement in research projects within the NDK, with funding available for various needs. **Finland**'s patient organisations can receive support from the Funding Centre for Social Welfare and Health Organisations (STEA) while **Sweden**'s patient organisations receive financial support from the Swedish Cancer Society, pharmaceutical companies and the National Board of Health and Welfare. In **Türkiye**, NGOs can apply for funding for various projects from a range of sources. **Norway** has substantial funding for user participation and patient engagement, but not specifically for citizen engagement. **Croatia** offers funding through public calls for proposals for general engagement in healthcare. In **Slovakia**, the Slovak League against Cancer organises the largest national fundraising event, Daffodil Day, and other smaller fundraising activities throughout the year to fund its programmes for oncological patients. **Italy** and **Ireland** reference European funded programmes, with Ireland's Irish Research Council contributing funds to the PPI Ignite network, which promotes public and patient involvement in health and social care research. In **France**, the government supports patient organisations via grants and subsidies, with individual funding dependent on each institution or sponsor. Finally, in **Austria**, self-help organisations operating nationwide can apply for funding of up to €15,000 per year for activities (without legal entitlement). The respondents noted that while there is limited funding for self-help organisations on a national and regional level and opportunities for patient organisations to participate in projects as a consortium partner, a comprehensive national funding scheme is lacking. Some funding is also available from the pharmaceutical industry for citizen engagement activities in health, which can be helpful, provided that a contractual agreement not to influence the outcomes of the activities is in place.

Transparency

The item on transparency asked whether participants are aware of any mechanisms or measures to ensure transparency within their country concerning the extent to which the input of citizen representatives has been considered in decision-making processes (e.g. publicly available opinion on legal statements, input from citizen representatives or any other form of public feedback or input). Transparency was also defined in relation to clear and open communication about the processes used to arrive at decisions and the extent to which input from citizens is considered (for more detailed information, see the survey template in the Appendix).

As shown in Figure 9 below, over half of the respondents (56%) reported that there are currently no mechanisms in place to ensure transparency in their country. A small proportion of respondents indicated that platforms for public feedback exist (17%), public feedback is made visible (17%) and contributions by citizens to formal documents/policy documents related to cancer are made visible in the protocols of meetings (17%). Finally, 22% of respondents are aware of mechanisms to ensure that accessible information is made available to the public to obtain insights into how public input was considered during decision-making processes. Another small proportion chose “other” (17%).

In the comment section, **France** noted that the level of transparency depends on the type of project in which citizens are involved and **Finland** specified that transparency depends on the individual organisations implementing engagement activities. **Norway** highlighted that while patient organisations and civil society organisations are asked for feedback, governmental consultations are typically not open to individual citizens. **Sweden** reported that patient representatives are included in most advisory panels, reference panels, national clinical guidelines and standards of care. **Croatia** mentioned online public consultations in the healthcare field as a common kind of transparency mechanism. Interestingly, **Poland** was preparing a report on the cooperation programme with non-governmental organisations containing information on all activities undertaken in this field (see the country profile for Poland for more details). **Ireland** provided an example of the Cancer Patient Advisory Committee meeting minutes being published publicly. When consultation is sought from citizens on policy in Ireland, consultation documents are published where appropriate. Finally, **Italy** and **Germany** reported a lack of awareness of such mechanisms.

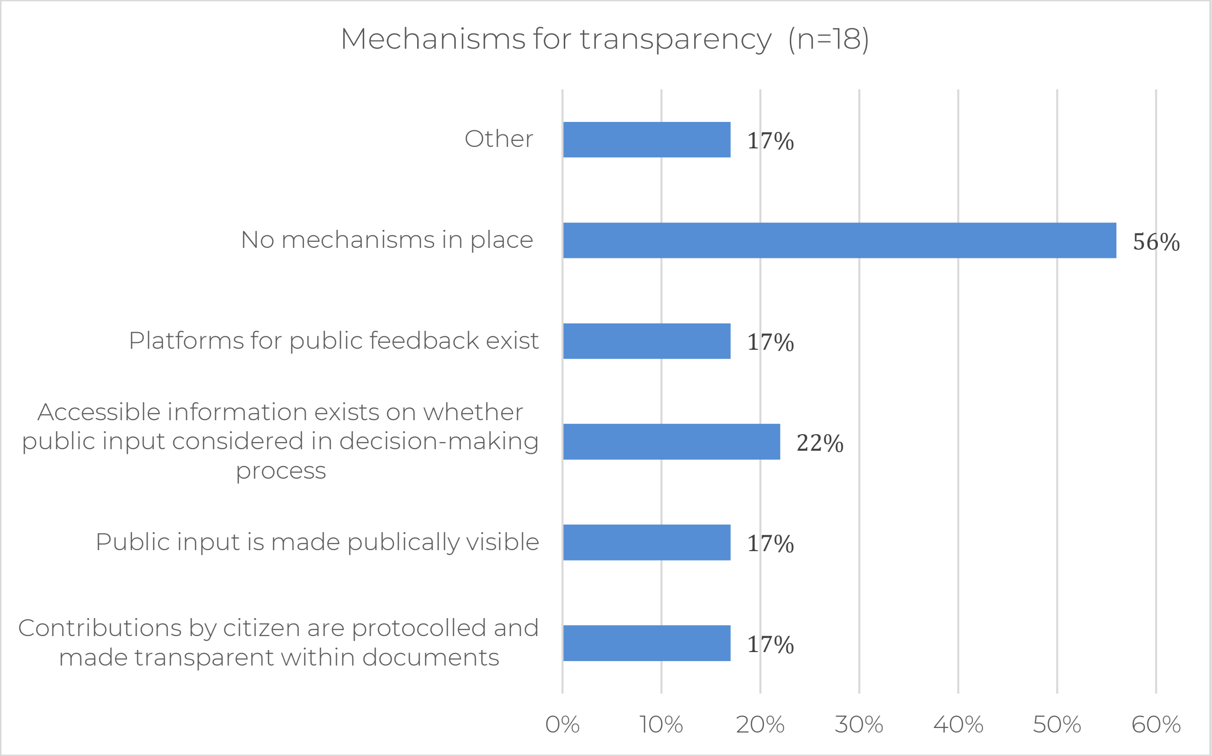

*Figure 9. Responses on transparency. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

Monitoring

On the question as to whether there is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement on cancer, most countries (67%) answered no. Another 28% responded "other" while 11% (**Germany** alone) reported to have monitoring mechanisms in place (see Figure 10 below).

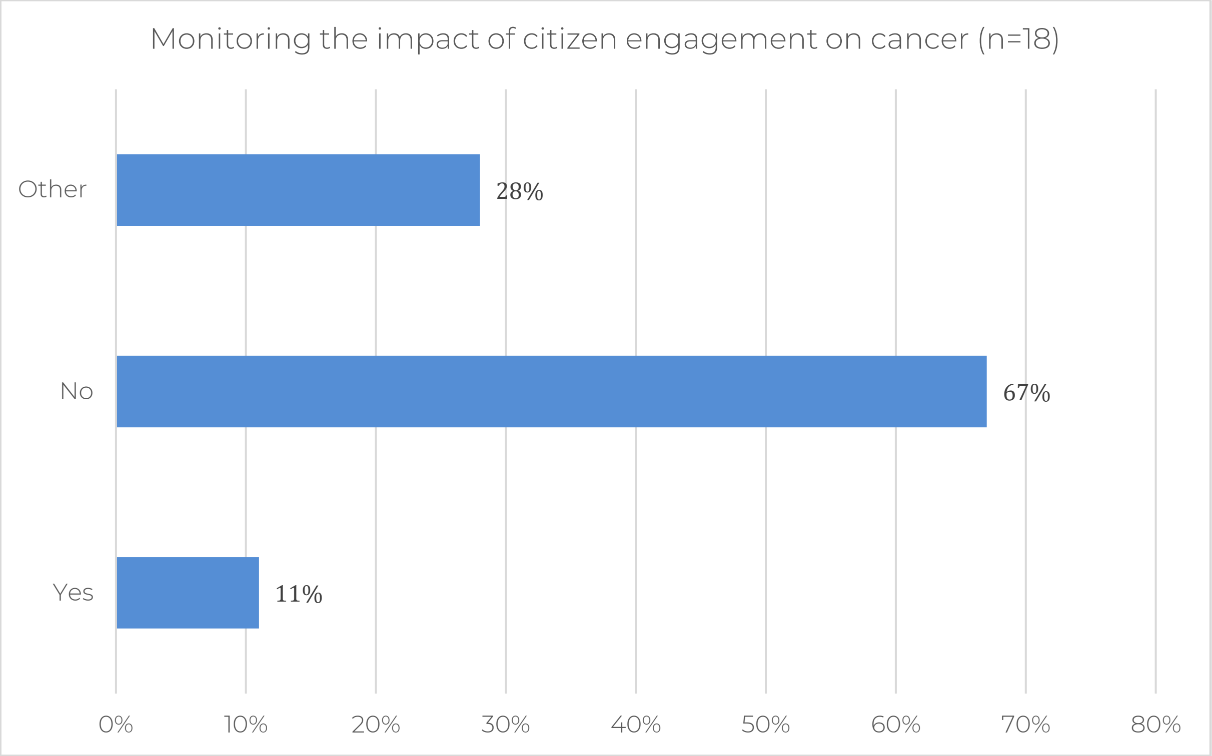

*Figure 10. Responses on the availability of monitoring mechanisms on the impact of citizen engagement on cancer. *Percentages refer to the number of respondents out of 18 who chose "yes" for a given question. Please note that the answer options were not mutually exclusive; several boxes could be ticked at once.*

Germany reported that patient involvement is a crucial component of the NCT concept, and its integration is evaluated as part of the regular assessment process. The incorporation of patients'/citizens' perspectives is progressively becoming the norm for BMBF funding measures and, in certain instances, for cancer-related foundations. It is also a criterion in the evaluation of funding applications. Other nations also provided feedback. For instance, **Norway** stated that while there is no formal monitoring, there is both reflection and piloting of actions in the Cancer Mission Hub Norway, focusing on user participation and citizen engagement. **Croatia**, in turn, indicated that the process is not systematic. However, there are some reports from patient organisations in their internal documents. In **Ireland,** monitoring is part of an ongoing discussion and was the focal point of the Irish Health Research Forum last year as well as the PPI Ignite and individual organisations. **France** also specified that they are currently in the process of developing monitoring mechanisms, which are not yet in place. France Strategy published a paper on this topic (see the country profile for France for additional information).

Good practices

Respondents were also asked to provide information on what they consider good practices i.e. existing activities, processes and regulations concerning citizen engagement in health, or specifically on cancer on a national level. The following overarching themes emerge from their answers:

- **Patient involvement:** Some countries emphasised the importance of patient involvement in cancer research and treatment. This includes the integration of patient perspectives in funding measures and decision-making processes (**France**, **Germany**, **Poland**).
- **Collaboration:** Collaboration between various stakeholders, including patient organisations, healthcare professionals and government bodies, is a commonly mentioned good practice. This collaboration often results in the co-creation of solutions aiming to directly address patient needs (**France**, Germany, **Ireland**, **Norway**, **Slovakia**).
- **Communication and transparency:** Countries stressed the importance of open dialogue, transparency and inclusivity in their practices. This is often achieved through seminars, forums, workshops and other interactive platforms (**Germany**, **Portugal**, **Slovakia**).
- **Capacity building:** Some countries highlighted the importance of capacity building among stakeholders. This includes providing resources, expertise and networking opportunities to facilitate knowledge exchange and collaborative action (**France**, **Portugal**).

The following list gives a very brief overview of some of the good practices mentioned by individual countries. More specific information (including links, etc.) will be available in the country profiles.

1. **Austria** mentioned ÖKUSS, the Austrian Competence and Service Centre for Self-Help, which has the task of providing support to self-help organisations nationwide and strengthening patient participation, as a good practice example. Specifically, ÖKUSS organises further training opportunities and publishes guidelines/orientation aids for those responsible for committees.

It is currently working on guiding principles for committee work. The organisation "Krebshilfe" was also mentioned as a good practice example, even if it cannot be directly categorised as a patient organisation. Thirdly, campaigns help put pressure on the government to improve patient engagement. Several projects were mentioned, for example a patient-reported outcomes portal by a hospital operator (Vinzensgruppe).

2. **Croatia:** A good practice was mentioned relating to the engagement of a cancer patient organisation in making and adopting the National Cancer Plan. However, the organisation is excluded from monitoring and assessing the implementation of the document.
3. **Czech Republic:** The respondents mentioned that French regulations are followed as good practice, but they were unable to cite the exact regulations.
4. **Estonia:** Empowering screening activities. Home-based testing for HPV. Vaccination of young people against HPV up to 18 years. Restrictions on advertising and selling alcohol and tobacco. State promotion of an active lifestyle (hiking trails and sports tracks). Active charity fund for cancer drugs not financed by the Estonian Health Insurance Fund.
5. **Finland:** Some cancer research projects have excellent collaboration with patient organisations but there are no nationally established structures or regulations concerning citizen engagement in health/on cancer. The Finnish Medicines Agency in collaboration with the network for rational pharmacotherapy research and EUPATI Finland has published a check list of patient engagement for researchers: Link: https://fimea.fi/-/rationaalisen-laakehoidon-tutkija-tutustu-potilaan-osallistumisen-tarkastuslistaan
6. **France:** The French National Cancer Institute (INCa) demonstrates commendable practices in citizen engagement through various initiatives and platforms (ample information will be available in the country profile).
7. **Germany:** As part of the German Presidency of the Council of the European Union, the German Federal Government issued a joint declaration on "Principles of Successful Patient Involvement in Cancer Research". The paper combines the views of patient organisations, cancer research, participatory research, the medical and healthcare professions, industry, research management, funding organisations and the policy-making level. The paper presents a shared vision; strategy, level and timing of involvement; communication, understanding and relationships; resources, knowledge and skills; methods and approaches; and ethical and legal aspects (https://www.gesundheitsforschung-bmbf.de/files/2021_06_01_Principles_Paper_bf.pdf). Germany also mentioned other working papers (see country profile).

8. **Ireland:** Ireland is advancing well to include citizen engagement in a meaningful way in cancer care and research. Continued collaboration is important (HRCI, PPI Ignite, NCCP) but some national guidelines on reimbursement and recognition of the role and expertise played by charities in this could be increased.
9. **Italy** mentioned some processes which are ongoing as a result of activities within the framework of EU-funded projects.
10. **Latvia:** Some discussions have taken place; these were good practices as citizens' voices were heard.
11. **Luxembourg:** Did not provide an answer.
12. **Malta:** Did not provide an answer.
13. **Norway:** Reflection and piloting of actions in the Cancer Mission Hub Norway focusing on user participation and citizen engagement. Norway also included several links: https://www.cancermission.no/aktuelle-saker/2023/felles-kronikk-om-kreft-i-drammen/; https://radio.nrk.no/serie/distriktsprogrambuskerud/DKBU01045823?utm_source=nrkradio&utm_medium=delelenke-ios&utm_content=prf:DKBU01045823; https://tv.nrk.no/se?v=DKOV98102523&t=447
14. **Poland** included various examples of citizen involvement, including patient organisations cooperating with the medical community and then with the Ministry of Health.
15. **Portugal** mentioned various good practices along with the relevant links. It was also mentioned that the National Programme for Oncological Diseases, Horizon 2030, includes two representatives of patient associations on its executive board.
16. **Slovakia:** Existing activities concerning citizen engagement in health, or specifically on cancer, within the country, are organised predominantly by NGOs and patient organisations. The Ministry of Health, together with the National Oncology Institute, patient organisations and health insurance companies, has launched a campaign for highlighting participation in cancer screening programmes.
17. **Sweden:** Did not provide an answer.
18. **Türkiye:** Implemented the Cancer Appointment System to increase participation in screening: family Physicians call the target populations in their regions individually and provide information about cancer screenings, inviting those who are eligible for screening to take part.

Recommendations

When asked for helpful recommendations on enhancing citizen engagement, there was ample insightful feedback on a wide variety of areas of engagement. These are summarised below.

An essential prerequisite for strengthening citizen engagement on cancer is to clearly define which population group/target audience is being addressed in each activity of engagement because there are areas of citizen engagement in which laypeople can be integrated well (e.g. a review of patient information) and areas in which a high level of expertise is required (HTA, outcomes, study designs, etc.). A distinction between citizen, patient, relative of a patient, (layperson), patient-expert and patient representative appear to make sense here. It is essential to determine which of these groups should be involved and for what purpose.

According to some countries, efforts should also focus on disseminating information about lifestyle habits and **screening programmes** through various channels including schools, healthcare centres, general practitioners and dental care facilities. Participation in screening programmes should be actively encouraged, utilising platforms like social media, TV and awareness events. Furthermore, information and information dissemination should be tailored to different demographics, including age, gender and level of education. Information materials should be available in plain language and multiple languages.

Regular **national information workshops** should be established to inform citizens about their potential involvement in research and treatment throughout the patient journey.

Another recommendation made by several countries is the **early involvement of citizens** in the sense of **agenda setting**. While patient organisations, for example, in the Netherlands, are consulted in scientific research, it often happens after the research protocol has already been written, leading to a mismatch between patients' priorities and the research questions addressed. This late consultation undermines the effectiveness of patient engagement. Therefore, there is a need to include patients and citizen input earlier in the process to ensure that their real needs are heard and reflected in healthcare and cancer care strategies and documents.

It is seen as essential by some countries **to establish feedback mechanisms** that enable citizens to monitor the impact/outcome of opinions/inputs provided to ensure a trust-based and transparent relationship between participants and the system.

Some counties mentioned that a key recommendation is to **provide comprehensive training** on how to engage with citizens, explaining the necessary aspects for success. There should be training possibilities for researchers and healthcare professionals as well as for patient advocates/representatives. This training should include not only advice on how to engage citizens but also on fostering partnerships between health professionals, researchers and stakeholders. Through inclusion and transparency, a collaborative environment can be created where citizens feel valued and able to contribute meaningfully to cancer initiatives.

Inclusive training possibilities should be provided for individual citizens/patients or specific target groups who come from economically or educationally disadvantaged backgrounds so that they can also be involved in decision-making processes.

The **creation of NCMHs** with shared responsibilities (including citizens) is also seen as beneficial. Germany mentioned a joint initiative, the National Decade Against Cancer (NDK), involving the BMBF (Ministry for Education and Research) and all relevant stakeholders active in the field of cancer research and cancer care. The goal of this 10-year programme is to improve prevention, diagnosis and treatment of cancer by engaging various interested groups (researchers, regulators, patients and their relatives) in the initiative. The NDK has done much to emphasise the importance of patient/community involvement. The central involvement of representatives in the Steering Committee and working groups was able to place important concerns in the right places.

Another recommendation for enhancing patient engagement is the **establishment of umbrella organisations/platforms** that represent all or groups of patient associations. This would be advantageous when there is a need for patient representation in committees. As an example of good practice, the Spanish association "Somos Pacientes" (https://www.somospacientes.com/) or the European Patient Forum (https://www.eu-patient.eu/) were mentioned.

The development of a **guide for health authorities outlining rules and mechanisms** for the involvement of citizens is seen as beneficial for national representatives and governmental organisations to enhance citizen engagement.

Such a guide should include guidelines regarding reimbursement and recognition of the role and expertise of civil society and patient organisations or individual citizens. Also, a data base /directory of good practices on citizen engagement activities for public consultation and for inspiration, is seen as helpful. Ideally this directory should be made available in respective native languages and English.

Some countries emphasised the **importance of allocating sufficient resources** for patient organisations to prevent conflicts of interest. For example, in Austria, participating stakeholders/respondents identified a need for independent basic/comprehensive funding of patient organisations, e.g. in the form of a fund or annual subsidy.

Another recommendation relates to the **role of the EU**. Here, systematic attention should be paid to **the consideration of citizen engagement** and **corresponding regulations** should be created. For example, citizen engagement could be demanded as a funding criterion for cancer-specific joint actions and care could be taken to ensure that the perspective of those affected is considered.

Summary of Results

The analysis highlights the diverse landscape of communication strategies, citizen engagement methods, regulatory frameworks, funding mechanisms, transparency and monitoring practices across countries. In the following section the results are summarised and analysed, structured according to the different categories of engagement.

Communication: The analysis reveals widespread use of various information channels, with social media and online platforms being the most common (100% of countries), followed by public health websites and portals (94%). A cluster of countries (including DE, EE, HU, LT, PL, SL, TR) utilise a comprehensive array of nine information channels, which likely enhances the reach and effectiveness of their health communication. Three countries (AT, NL, SE) indicated seven information channels. Two countries reported five (CZ, NO) and six countries three to four information channels (FI, FR, IE, IT, LU, MT). The accessibility and comprehensibility of communication is most frequently rated as “Generally clear and accessible, but there might be room for improvement in certain areas” (n=10, 56% – DE, EE, HR, IE, LU, MT, NL, PT, SE, SK). Two countries rated them with “Highly accessible to all” (SK, TR) and four countries reported significant room for improvement (AT, IE, PL, SK).

Citizen engagement methods: Citizen engagement is varied, with collaborative research projects and consultations being the most common methods, used by 83% of the countries surveyed. The range of engagement methods varied considerably too. Individual countries stand out positively due to the use of five (AT, DE, FR, NL, NO, SK) or four (IE, SE) participation methods. Five countries reported three methods (FI, HR, IT, LU, PL), five reported two methods (CZ, EE, MT, PT, TR) and one country reported only consultations (LV).

Training for citizen engagement on cancer shows a mixed picture. Data from the initial 18 respondent countries reveal that the majority of these countries have at least one form of training material related to citizen engagement, designed for a broad public audience, including individuals, civil society and patient advocacy groups. Out of the 18 countries, six (33%, including AT, FR, HR, IE, NL, SK) indicated the presence of educational programmes and twelve (67%, including AT, DE, EE, FR, HR, IE, MT, NL, NO, PL, SE, SK) reported the availability of educational materials on citizen engagement specifically related to cancer. Regarding training for healthcare professionals, the survey results indicate a wide range of educational materials available, with 33% of respondents reporting the availability of materials both with (AT, FR, HR, IE, NL, PT) and without specific reference to cancer (AT, FI, NL, NO, PT, SE). Furthermore, 22% of responses (EE, NL, NO, PT) highlighted the existence of training programmes related to citizen engagement on cancer while 17% (CZ, HR, IE) indicated the presence of cancer-specific training programmes in their countries.

Regulatory frameworks vary significantly across countries. Regarding regulatory frameworks concerning who may represent citizens' interests, 44% indicated the existence of legally binding references in their country (DE, FR, HR, NL, NO, PL, PT, TR) while 39% reported the absence of such regulations (EE, FI, IE, LU, LV, MT, SK). 33% of the respondents indicated (in part, additionally to the previous option) the presence of unspecific references (AT, CZ, EE, FR, IE, NL) regarding who may represent citizens' interests in their country while 33% indicated "other", also partly in addition to the first option (FR, IE, IT, PL, SE, SK). Concerning citizen engagement activities, the same response rate was given by the same countries with regards to not having any regulations in place (39%) or 7 countries (DE, FR, HR, NL, NO, PL, TR). Five countries, or 33% again, reported having legally binding regulations (FR, HR, NL, PL, TR) and 33% were reported to have unspecific references. Again, sometimes countries indicated the presence of several options, so the responses were not mutually exclusive (CZ, FR, NL, NO, SE, SK); "other" was clicked by 22% (FR, HR, NL, PL, TR).

Funding: Funding for citizen engagement in health and on cancer is diverse. Some countries (including NL) provide direct funding to citizens involved in research projects and advisory boards. Others (including AT, DE, FI, SE) offer some kind of funding for patient organisations. For example, in Austria, self-help organisations operating nationwide can apply for funding of up to €15,000 per year for activities (without legal entitlement). A few countries (TR) have NGOs that can apply for project funding from various sources. However, some countries (NO) lack specific funding for citizen engagement, despite having substantial funding for user participation and patient engagement. In contrast, some countries (FR, SK) rely on national fundraising events and government support. The diversity of these funding mechanisms reflects the unique approaches each country takes towards supporting citizen and patient engagement in health. Nevertheless, the recommendations show that overall, more funding is needed and that the funding needs to be set up in a way that ensures independent outcomes for citizen engagement activities.

Transparency in citizen engagement activities is another area where improvement is needed. Over half of the respondents (56%) indicated that there are no mechanisms in place to ensure transparency in their countries. Some countries (AT, DE, IT) reported a lack of awareness of such mechanisms, while others (FI, FR) noted that the level of transparency depends on the project or the organisations implementing engagement activities. Others (HR, NO, SE) indicated that they had specific mechanisms for feedback and patient representation in advisory panels and national clinical guidelines. Finally, one country (PL) was in the process of developing materials or already publishing meeting minutes publicly to ensure transparency.

Monitoring: Similar to transparency, monitoring of citizen engagement activities is lacking in most countries (67%, including AT, CZ, EE, FI, FR, HR, HU, LU, LV, MT, NL, PT, SK, TR). The lack of dedicated monitoring mechanisms may hinder the evaluation and continuous improvement of engagement practices.

Conclusions

The analysis reveals a complex, varied and very interesting landscape of communication strategies, citizen engagement, and regulatory and funding mechanisms across different countries. While there are outstanding examples of comprehensive strategies and robust frameworks, the overall picture indicates significant disparities and areas for improvement for example of regulatory framework, transparency and monitoring. Enhancing training, transparency and monitoring, along with establishing consistent regulatory and funding mechanisms, could significantly improve the effectiveness of citizen engagement in health policy across Europe.

To enhance citizen engagement in cancer initiatives, the key recommendations from this analysis include:

1. **Define Target Audience:** Clearly identify which group (citizen, patient, expert, etc.) is being engaged for specific activities.
2. **Information Dissemination:** Spread information on lifestyle habits and screening programs through diverse channels, tailored to demographics, and in accessible language and multiple languages.
3. **Early Involvement:** Engage citizens early in the research process to align with their priorities and needs.
4. **Feedback Mechanisms:** Establish systems for citizens to monitor the impact of their contributions.
5. **Training Programs:** Provide training for researchers, healthcare professionals, and patient advocates to foster effective citizen engagement and partnerships.
6. **Inclusive Training:** Offer training for economically or educationally disadvantaged groups to involve them in decision-making.
7. **Shared Responsibilities:** Create collaborative structures, like Germany's National Decade Against Cancer, to include citizens in cancer care initiatives.
8. **Umbrella Organizations:** Establish platforms representing patient associations for effective representation.
9. **Guidelines and Best Practices:** Develop guides and directories for engaging citizens, including reimbursement guidelines and good practice databases.

10. **Resource Allocation:** Ensure sufficient independent funding for patient organizations to avoid conflicts of interest.
11. **EU Role:** Integrate citizen engagement into EU funding criteria and regulations for cancer-specific actions.

Next steps

Data visualisation and results published on the website: Following the completion of this report, which will be published on the ECHoS Website, incoming data from further responding countries who missed the deadline will be analysed continuously and the results will be added to the visualisation of the data on the website. This visualisation is planned in the form of a table including the four main categories (Communication; Methods and opportunities; Training and education; Processes, regulations and policy aspects) and a clickable map in each category. A summary of the findings for each country will be published in a textbox within each category. The information will be provided by GÖG and uploaded to/programmed in the website by a team of developers working together with the communication officer (also a member of WP6) of the coordinating ECHoS institution, AICIB.

As of April 2024, several meetings had taken place between GÖG (Task 6.2), the communication officer (Task 6.1 lead) as well as the developing team. The plan mock-up is under preparation and will be presented by AICIB on 7 May 2024 at the executive board meeting. The visualisation is anticipated to be finalised around May/June 2024. In the meantime, the report will be published on the website as a PDF. Joint Action is planned to repeat the survey in around May 2025 and to develop the website into a maturity map.

2nd Landscape Analysis: To observe developments in the field of citizen engagement, a second landscape analysis will be conducted in March 2026. For this purpose, the survey will also be distributed.

References

1. European Commission, Directorate-General for Research and Innovation, Baeck, P.; Fuller, R.; Edgar, C.; *et al*. (2023), Citizens' awareness of EU missions and opportunities for citizen engagement – Results from a multi country survey, Publications Office of the European Union, https://data.europa.eu/doi/10.2777/493830

2. GÖG (2024), Survey on Citizen Engagement in Cancer [online] Gesundheit Österreich GmbH, https://survey.goeg.at/index.php/218939?lang=en

3. Kale, Swarali; Hirani, Shoyeb; Vardhan, Sauvik *et al*. (2023): Addressing Cancer Disparities Through Community Engagement: Lessons and Best Practices. Cureus. 2023 Aug 14;15(8), https://doi.org/10.7759/cureus.43445

4. Leader, Amy E.; Melillo, Rebecca J.; Greene, Quincy *et al*. (2023): Engaging community members in cancer research: an assessment of an NCI-designated cancer center. Cancer Causes Control 34 (2023), 307–319, https://doi.org/10.1007/s10552-022-01666-8

5. OECD (2022), OECD Guidelines for Citizen Participation Processes. OECD Public Governance Reviews, Paris, https://doi.org/10.1787/f765caf6-en.

6. Ricciardi, Walter (2021): EU Missions. Concrete solutions for our greatest challenges. The European Strategy on cancer [online]. European Commission https://oeci.eu/Attachments/Paris_23/European_Cancer_Mission.pdf

7. Rychetnik, Lucie; Carter, Stacy M.; Abelson, Julia *et al*. (2013): Enhancing Citizen Engagement in Cancer Screening Through Deliberative Democracy. Journal of the National Cancer Institute (JNCI), Volume 105, Issue 6, 20 March 2013, 380–386, https://doi.org/10.1093/jnci/djs649

8. WHO (1978), Declaration of Alma-Ata. International Conference on Primary Health. World Health Organization, Alma-Ata, 6-12.

Appendix - Completed SURVEY responses

SURVEY template

Survey response	
Response ID	
Date submitted	
Please include the following information:	
[Which country are you completing this survey for?]	
[Which institution are you representing ?]	
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers…)?]	
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	
[Healthcare Providers and Clinics]	
[Community Events and Workshops]	
[Social media and Online Platforms]	
[Printed Materials and Brochures]	
[Local News and Media]	
[Patient Support Organizations]	
[Government Campaigns]	
[Educational Institutions and Schools]	
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	

[3. The accessibility and clarity of communication vary.]	
[4. Some improvements are needed.]	
[5. There is significant room for improvement.]	
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	
[2. Consultation]	
[3. Patient Advisory Boards]	
[4. Community Workshops and Forums]	
[5. Online Platforms and Surveys]	
[6. Collaborative Research Projects]	
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	
[There are cancer-specific educational materials]	
[There are general training/educational programmes without specific reference to cancer]	
[There are educational materials without specific reference to cancer]	
[There are no corresponding educational/training programmes]	
[There are no corresponding educational materials]	

What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	
[There are cancer-specific educational materials]	
[There are general training/educational programmes without specific reference to cancer]	
[There are educational materials without specific reference to cancer]	
[There are no corresponding educational/training programmes]	
[There are no corresponding educational materials]	
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health	
[There is no regulation in place - it is not formally defined who can represent citizens]	
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	
[There is no regulation in place - it is not formally defined who can represent citizens]	
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please	

specify whether in health or cancer specifically]	
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	
[Other, please specify]	
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	
[There is funding for patient organisations - please specify]	
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	
[There is accessible information on whether public input was considered in decision making process]	

[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	
[There are no mechanisms to ensure transparency]	
[Other, please specify]	
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	
[No]	
[Other, please specify]	
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	.

Austria

Survey response	
Response ID	51
Date submitted	26.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Austria
[Which institution are you representing ?]	Austrian National Public Health Institute GÖG
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Workshop with members of MAG Cancer and Experts and patient advocates in the cancer field; written feedback on drafted answers
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Information portal: https://gesundheit.gv.at For the palliative setting, www.hospiz.at and www.palliativ.at
[Healthcare Providers and Clinics]	Institutions such as regional hospitals (e.g. Vorarlberg regional hospitals) that organize information events, events for "lay-people" Communication trainings for health professionals: https://oepgk.at/website2023/wp-

	content/uploads/2023/04/factsheet-gesundheitsinformation-in-der-onkologie-barrfrei.pdf
[Community Events and Workshops]	Cancer School Vienna - https://ccc.meduniwien.ac.at/cancerschool/ Onkip - Oncological information portal Upper Austria (www.onkip.at)
[Social media and Online Platforms]	[Social media and Online Platforms] Platform for patients and relatives https://selpers.com/krebs/krebsfrueherkennung/ https://selpers.com/kurs/bestmoegliche-therapie-bei-krebs/ Website: Focus Patient www.focuspatient.at Kurvenkratzer online magazine: www.kurvenkratzer.com https://www.kurvenkratzer.com/magazin
[Printed Materials and Brochures]	Early detection of breast cancer https://www.frueh-erkennen.at/
[Local News and Media]	
[Patient Support Organizations]	Allianz der onkologischen Patientenorganisationen (Alliance of oncological patient organisations) https://dieallianz.org/ Various indication-specific patient organisations (e.g. colorectal cancer, breast cancer, etc.), e.g. see member of Alliance of oncological patient organisations Various websites of patient-

	organisations are important sources of information Divers material from patient organisations Various events organised by patient organisations
[Government Campaigns]	https://www.sozialministerium.at/Themen/Gesundheit/Nicht-uebertragbare-Krank-heiten/Krebs.html
[Educational Institutions and Schools]	Pädagogische Hochschulen Österreich (Universities of Teacher Education Austria) organise educational events Educational institutions and schools Cancer School Vienna - https://ccc.meduniwien.ac.at/cancerschool/
[Other]	Krebshilfe Österreich (Cancer Aid Austria) (materials, events, flyers etc.) + individual national organisations Austrian Society for General Medicine -> EPM Network (Citizens' folder
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	Yes (partly)

	Participants rate between 4 and 5: It is difficult to find the right information even though there are many materials available. still many challenges to be overcome: • materials need to be more accessible to lay-people and people with lower education • lack of information material in different languages. • one of the reasons of why accessibility is low could be the lack of cooperation among different stakeholders/groups. • there is also a very clear lack of culturally sensitive patient material
[5. There is significant room for improvement.]	Yes (partly)
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	National: • Related to cancer: o Boards: MAG Cancer; oncology advisory board; Screening committee on Cancer; Advisory Board for rare diseases; (Hardly any influence on decisions) o Patient organisations in the respective fields (individual oncological indications) o Room for improvements: Research: especially in the research field there are significant gaps in citizen/patient engagement. • Not related to Cancer: Patient

	representative course (Austrian competence and service centre for self-help), https://oekuss.at/kurs; general consultation for draft laws
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Interviews with individuals (counselling) available in Austria, e.g. in the field of psychiatric illnesses (less so in the field of oncology, where there is potential for improvement)
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	No
[5. Online Platforms and Surveys]	Meine KrebsHilfe: https://meinekrebshilfe.net/portal/public/app/#/home Focuspatients.at https://www.focuspatient.at/
[6. Collaborative Research Projects]	Focus Patient, „Patient Study advocates" (opportunities to participate to clinical studies) Ludwig Boltzmann Gesellschaft Open Innovation in Science: Shttps://ois.lbg.ac.at/ / https://ois.lbg.ac.at/cancer-mission-lab/ Development of screening questionnaires on NF for doctors on the initiative of patient organisations https://ccp.meduniwien.ac.at/en/forschung-und-entwicklung/ppie-patient-

	and-pub-lic-involvement-and-engagement/
[7. Other]	Representatives of patient organizations are involved in the preparation of guidelines (rarely in AT, also rather recommendation)
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	there is not much in AT, there is support from the industry to enhance knowledge generation for patient organisations Cancer School Vienna - https://ccc.meduniwien.ac.at/cancerschool/ LBG Open Innovation in Science (general trainings and educational materials/webinars) Indication-independent training from EUPATI (website, toolbox also in German and webinars on topics such as patient engagement/involvement HTA) many indication-specific webinars (Vienna Brain Tumour Congress) Alliance of Oncology Patients is trying to create training opportunities in Austria in order to provide a professionalisation opportunity to offer qualified people as colleagues.
[There are cancer-specific educational materials]	No

[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	Not related to Cancer: Patient representative course (Austrian competence and service centre for self-help), https://oekuss.at/kurs; EURORDIS Open Academy: https://openacademy.eurordis.org HTA Training with/by UMIT Tirol: https://www.eucapa.eu Agency for patient communication: https://www.kurvenkratzer.com/magazin-kolumne/mit-uns-statt-ueber-uns/ https://www.kurvenkratzer.com/magazin/mitsprache-woanders-ist-das-gras-im-mer-gruener/
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	Remark: education/training need not to be cancer specific; Attempt to develop a training programme with the Alliance of Oncology Patients was blocked by stakeholders
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	Conversation training for healthcare professionals: https://oepgk.at/website2023/wp-

	content/uploads/2023/03/produktfolder-onkologie-2022.pdf
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	EUPATI essentials: https://eupati.eu/eupati-essentials/
[There are educational materials without specific reference to cancer]	Guidelines for committee chairs: https://oekuss.at/sites/oekuss.at/files/OeKUSS-Leitfaden-GREMIUM%20bf.pdf Kurvenkratzer Link (Serie: patient advocacy) https://www.kurvenkratzer.com/tag/advo-cacy/
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health	
[There is no regulation in place - it is not formally defined who can represent citizens]	There are individual advisory bodies in which patient organisations are members. Participation is anchored in the rules of procedure, but there is no legal framework that provides for participation
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically

[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health	
[There is no regulation in place - it is not formally defined who can represent citizens]	There is a lack of a common understanding of patient involvement, defined rules on who can represent patient interests and basic funding for patient organisations
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	There are legally binding regulations on who can represent citizens interests – please specify whether in health or in cancer specifically
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No

[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	No
[Other, please specify]	There is limited funding for self-help organizations on national (up to 15.000 Euro/year for 3 activities) and regional level https://www.gesundheitskasse.at/cdscontent/?contentid=10007.893545&portal=oegkportal Opportunity to participate in projects as a consortium partner Funding from industry for self-help organisations; these must not contractually influence outcomes
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Cancer specific Krebshilfe as an example for an organisation, which build political pressure via campaigns even if not directly categorised as a patient organisation. Project of a hospital operator (Vinzensgruppe) Begleit-App (on keep, patient reported outcome portal)

	non-cancer-specific: health targets Austria Intersectoral process for defining and processing health objectives https://gesundheitsziele-oesterreich.at/ Citizens' councils on the future of health promotion: https://agenda-gesundheitsfoerderung.at/faq_buerger_innenrat#:~:text=oben%20zum%20Inhaltsverzeichnis-,Was%20ist%20der%20B%C3%BCrger%3Ainnen%2DRat%20%E2%80%9EZukunft%20Gesundheitsf%C3%B6rderung%E2%80%9C,S%C3%BCden%20und%20Osten%20%C3%96sterreichs)%20durchgef%C3%BChrt.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No

[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	There are no general rules on publicity. Some boards publish the minutes of their meetings Pharmaceutical industry declares contributions (but in very few cases are reflected on the websites) Social pressure is increasing to declare more, but there are currently no existing regulations on transparency. It is not transparent on the basis of which criteria organisations are invited to represent patient interests Need for transparency for the problem between desired patient involvement (re-search and development / patient reported outcomes) and permissible framework conditions
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	
[No]	There is no national monitoring of the impact of engagement. However, since 2023, the National Public Health Institute has published a list of the proportion of projects with citizen/patient participation.
[Other, please specify]	

What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	Specifically for Austria independent basic funding for patient organisations - Independence can only be guar-anteed by a broad range of funders A health economic study in Austria would be desirable, where the services of Austrian self-help and patient organisations are recorded, and the value of these ser-vices is calculated. This would make it clear what would happen if the self-help groups/patient organisations were to disappear Legal framework is needed to define involvement/engagement and guidelines/recommendations/ a common understanding on the necessary requirements/steps to be taken to get to these legal frameworks; Patient participation must also be considered locally/regionally or adapted regionally, with local contact points Monitoring of patient engagement which allows to improve Training opportunities for patient advocates /representatives (also in German) + It must be possible to involve those affected who do not have an academic education or to in-volve different target groups (including

	educationally disadvantaged groups) in decision-making processes. It is important to raise public awareness of initiatives. Increase willingness to work with other stakeholders A calendar of events in which events organised by patient organisations can also be announced would certainly be helpful There are areas of citizen participation in which "lay people" can be used very well (e.g. review of patient information), and areas in which a high level of expertise is required (HTA, outcomes, study designs,...). Because of that it is an essential prerequisite for strengthening citizen engagement in cancer to clearly define which group is being ad-dressed in each case. A distinction between citizen, patient, relative of a patient, (lay persons), patient-expert und Patient representation appears to make sense here. It is essential to determine which of these groups should be involved and for what purpose. In general: There are existing best practices (networks such as EURACAN, European Reference Network (ERN PaedCan) good example NL: regular hearings where patients/citizens are included and can ask questions.

	UK has a comprehensive regulatory framework in place (PPI) for patient engagement. There are existing models which can be taken as a good practice. CZ: patient council for different fields, which are involved in all aspects. 10 GÖG DE: https://www.dekade-gegen-krebs.de/de/wir-ueber-uns/aktuelles-aus-der-dekade/_documents/allianz-fuer-patientenbeteiligung/allianz-fuer-patien-tenbeteiligung Methods such as community advisory boards, which are already used by European umbrella organisations, could also be used in AT

Česko

Survey response	
Response ID	42
Date submitted	18.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Česko
[Which institution are you representing ?]	Institute of Hematology and Blood Transfusion
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	collecting written answers, calls
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://www.linkos.cz/onkologicka-prevence/, https://www.onconet.cz/index-en.php, https://www.nzip.cz/
[Healthcare Providers and Clinics]	Yes
	https://www.mou.cz/en/

[Community Events and Workshops]	Yes
	https://onkofit.cz/
[Social media and Online Platforms]	Yes
	https://www.facebook.com/wtfcncr/
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organizations]	Yes
	https://www.stopa-zs.cz/, https://www.lpr.cz/, https://hlaspacientu.cz/, https://www.amelie-zs.cz/en/
[Government Campaigns]	No
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	Yes
	Communication varies from source to source availability in different languages, clarity of

	information, reaching all groups, p.e. young groups for prevention or older groups that don't use so much internet. Large proportion of communication lies on the specific care provider institutions.
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	There are preventive counselling services, online by the Czech Oncological Society (https://www.linkos.cz/onkologicka-prevence/poradna-o-prevenci/) Prague Marathon – Runner for Cancer Warriors - https://allysonwhitney.org/event/volkswagen-prague-marathon-2023/ National phone line for tumours: https://www.lpr.cz/akce-a-projekty/nadorova-linka The League against Cancer, organizes many activities, listed here: https://www.lpr.cz/akce-a-projekty
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	No
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes

	European Melanoma Day: https://www.denmelanomu.cz/evropsky-den-melanomu/
[5. Online Platforms and Surveys]	Yes
	5. Information portal for cancer patients: http://www.ciop.cz/
[6. Collaborative Research Projects]	No
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes
[There are no corresponding educational materials]	Yes

What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	Yes
	Education for young doctors https://www.loono.cz/en
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	Institution specific programmes
[Other comment]	Many specific programmes are ongoing withing different institution and departments, there is no systematic reporting or evidence.
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	

[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	Patients can be represented through patient's organisations, with clear rules how the organisation can be formed and function. Clear role in some legislation processes i.e. https://www.pacientskyhub.cz/
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes

	Ministry of Health published rules and guidelines for patient organisations, including cancer, if these organisations wish to be included on the ministry run website https://www.pacientskyhub.cz/
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	No

Estonia

Survey response	
Response ID	56
Date submitted	26.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Estonia
[Which institution are you representing ?]	Tartu University Hospital
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	meeting
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Cancer Centre
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	Screening activities on the website of Estonian Health Insurance Fund. www.tervisekassa.ee
[Healthcare Providers and Clinics]	Yes

	websites of the hospitals (screening) and cancer centres, booklets in appointment rooms, notifications for physicians (notification of screenings for screening target groups in digital health records)
[Community Events and Workshops]	Yes
	hospitals and cancer centres, cancer awareness events, Charity Foundations -ww.kingitudelu.ee, Estonian Cancer Society (patient organization)
[Social media and Online Platforms]	Yes
	podcasts on screening (Estonian Health Insurance fund), different charity events and notifications www.kingitudelu.ee - main cancer charity foundation in Estonia
[Printed Materials and Brochures]	Yes
	Estonian Cancer Society (patients' organisation) www.cancer.ee
[Local News and Media]	Yes
	advertisements for screening activities
[Patient Support Organizations]	Yes
	see above
[Government Campaigns]	Yes
	HPV vaccination and screening under Estonian Health Insurance Fund and

	Estonian Health Board (www.terviseamet.ee)
[Educational Institutions and Schools]	Yes
	HPV vaccination awareness events locally, recruitment to cancer scientific projects (e.g. Tartu University and genetic based breast cancer screening project, lung cancer screening pilot project))
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	information mostly on paper or to read, need of more visual and more easily accessible context.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Prevention cancer screening (cervical, breast, colon cancer) new cancer screening projects' pilot were publicly

	discussed in media - lung cancer screening, breast cancer genetic risk-based screening treatment Occasionally in media about new treatment modalities Multistakeholder events 2-3 times per year discussing the accessibility for innovative cancer drugs Survivorship Conferences organised by cancer society and cancer centres.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	No
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes
	Cancer centres organise events for the management of cancer related issues for patients and their families.
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	Yes
	Cancer patients' organizations were involved in genetic risk-based breast cancer screening project's events (BRIGHT project)
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	

[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	Under Estonian National Cancer Plan the National Institute for Health Development in collaboration with specialists' organizations publish in media (journal's websites and social media) the series of educational information to detect early symptoms of cancer.
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No

[There are general training/educational programmes without specific reference to cancer]	Yes
	information about local and national cancer societies (patient organizations)
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
	patient organizations
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	Estonian Patients Union
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No

Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	patients' councils in National Hospital Framework hospitals
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	Yes
	Estonian Cancer Society from state budget, minimal amount
[Other, please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your	

country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Empowering screening activities, home-base testing for HPV. Vaccination of boys and youth against HPV up to 18 years. Alcohol and tobacco publicity and selling restrictions. State promotion of active lifestyle (hiking and sporting tracks). Active Charity Fund for non-financed (by Estonian Health Insurance Fund) cancer drugs.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No

[There are no mechanisms to ensure transparency]	Yes
	there are no mechanisms in place
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
	no known monitoring
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	engagement of citizens and patient organizations into cancer-related legislative and organizational topics.

Finland

Survey response	
Response ID	35
Date submitted	15.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Finland
[Which institution are you representing ?]	HUS / FICAN
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Collecting information from partners and websites
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Other
	Cancer Society of Finland (CSF)
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	No
[Healthcare Providers and Clinics]	Yes

	There are cancer patient advisory boards in many hospitals, and they inform about the opportunities to participate in their websites. Example 1. https://syovanhoitokeskus.pshyvinvointialue.fi/asiakasraati Example 2. https://www.hus.fi/tietoa-meista/kehittaminen/asiakasosallisuus, Example 3. https://www.pirha.fi/web/guest/palvelut/sairaalat-tays/syopa/tays-syopakeskuksen-potilasraati
[Community Events and Workshops]	No
[Social media and Online Platforms]	Yes
	EUPATI Finland and patient organisations are active on social media incl. Facebook, LinkedIn, Twitter and Instagram and share information about engagement opportunities.
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organizations]	Yes
	EUPATI Finland shares information about opportunities for patient involvement: https://fi.eupati.eu/; Cancer patient organisations and Regional Cancer Associations share information about opportunities to get involved, e.g. https://www.pohjois-savonsyopayhdistys.fi/ajankohtaista/ver

	kkouutiset/tule-mukaan-kys-syovanhoitokeskuksen-asiakasraatiin/
[Government Campaigns]	No
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	Yes
	Information is usually only in Finnish, and there are no comprehensive communication strategies, plans or materials regarding citizen engagement in health and/or specifically cancer.
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Possibility to participate in cancer patient advisory boards at the university hospital(s), mainly related to cancer care in the specific hospital. Some cancer

	research projects collaborate with patient organisations and/or have patient advisory boards.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	COHERE Finland publishes draft recommendations on hospital medicines (mostly for treating cancer) for public consultation: https://www.otakantaa.fi/fi/hankkeet/62/
[3. Patient Advisory Boards]	Yes
	Cancer patient advisory boards exists in most of the university hospitals in Finland
[4. Community Workshops and Forums]	No
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	Yes
	An example of a collaborative research projects is iCAN Digital Precision Cancer Medicine Flagship: https://ican.fi/governance/
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives,	

patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	Yes
	EUPATI Finland has training activities, which are open to all patients or interested stakeholders regardless of disease type (https://fi.eupati.eu/). Finnish Medicines Agency Fimea has a Patient advisory board for patient organisation representatives to inform and engage civil society and patient representatives: https://fimea.fi/en/development_and_hta/patient-advisory-board
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	

[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	Yes
	The Finnish Institute for Health and Welfare publishes materials on citizen engagement: https://thl.fi/aiheet/sote-palvelujen-johtaminen/asiakas-palveluissa/asiakasosallisuus-palvelujarjestelmassa
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please	No

specify whether in health or cancer specifically]	
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	Yes
	Patient organisations can receive support from the Funding Centre for

<table>
<tr><td></td><td>Social Welfare and Health Organisations (STEA): https://www.stea.fi/en/</td></tr>
<tr><td>[There is funding for patient organisations - please specify]</td><td>No</td></tr>
<tr><td>[Other, please specify]</td><td>No</td></tr>
<tr><td colspan="2">Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.</td></tr>
<tr><td></td><td>Some cancer research projects have excellent collaboration with patient organisations, but there are no national established structures or regulation concerning citizen engagement in health / cancer. Finnish Medicines Agency in collaboration with the network for rational pharmacotherapy research and EUPATI Finland has published a check list of patient engagement for researchers: https://fimea.fi/-/rationaalisen-laakehoidon-tutkija-tutustu-potilaan-osallistumisen-tarkastuslistaan</td></tr>
<tr><td colspan="2">To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?</td></tr>
<tr><td>[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]</td><td>No</td></tr>
</table>

[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
	Transparency depends on the organisation implementing engagement activities.
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	No
[Other, please specify]	Yes
	Evaluation depends on the project / engagement activity.
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	

	Recommendation for national authorities on allocating sufficient resources for citizen and patient engagement.

France

Survey response	
Response ID	60
Date submitted	03.04.2024
Please include the following information:	
[Which country are you completing this survey for?]	France
[Which institution are you representing ?]	French National Cancer Institute (INCa)
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Collecting answers from colleagues from the "Living Lab & Health Democracy" Mission within the French National Cancer Institute
Which other stakeholders/institutions were included in gathering information for responding the survey?	
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	No
[Healthcare Providers and Clinics]	Yes
	Information about opportunities can be provided through healthcare providers but it is not institutionalized, it depends

	on the healthcare provider and its links to cancer patient support organisation
[Community Events and Workshops]	Yes
	Opportunities/activities for citizen engagement in cancer are mostly coordinated through Patient support organisation.
[Social media and Online Platforms]	Yes
	Mostly through social networks linked to institutions and associations fighting cancer in France. Each “sponsor” publishes its own "ad"; some associations may aggregate different ads but not often.
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organizations]	Yes
	Opportunities/activities for citizen engagement in cancer are mostly coordinated through Patient support organisation.
[Government Campaigns]	No
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No

[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	Yes
	The understandability is really improving, and we now achieve a good level of understanding. However, accessibility could be improved, especially about where to find information. It is still challenging to communicate our needs directly to citizens (lost in the flow of information). Low rate of answers.
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	The French National Cancer Institute aims to systematically involves citizens in its actions to fight cancer: including people with cancer, their families, users of the healthcare system, and professionals in the healthcare, social and research sectors. This is reflected in a number of concrete measures, including: - The Institute's Stakeholder Relations Charter, which formalizes the Institute's objectives and commitments to improving stakeholder involvement. - The Health Democracy Committee, a

	permanent consultative body reporting to the President of the Institute, which brings in the experience and viewpoints of users and professionals in the field. This Committee is currently being renewed. The Health Democracy Committee is made up of 28 members with varied profiles and skills: First, the users' College (14 members) represents the views of cancer patients, users of the healthcare system, caregivers and relatives. Second, the College of Professionals (14 members) represents all professionals involved in the fight against cancer - healthcare, medico-social and research professionals. - Dialogue with citizens, users and professionals of the healthcare system in several consultation initiatives: on breast cancer screening in 2015, and more recently on the proposed ten-year strategy to combat cancer in 2020. The ten-year strategy (2021-2030) now includes actions to improve citizens' engagement. - The creation of a Health Democracy mission within the Institute, responsible for coordinating the Health Democracy Committee. It also aims to support the Institute's management in involving users and professionals in their programs and working methods, and more broadly to listen to and relay the expectations of the field and society in the fight against cancer. - The French National Cancer Institute also launched a Living Lab, a space for sharing, reflection and action, with the ambition of initiating dynamics between players

	in order to produce innovative solutions to meet the needs expressed by patients, by placing them at the heart of the approach. The Living Lab focuses on the development of solutions and tools for all stakeholders, to help them better understand their care pathways. The role of the patient and his or her inclusion in the definition of solutions is essential, and all transdisciplinary skills are called upon. The Living Lab supports projects with three objectives: Meet a real need expressed by our audiences; Involve our publics in all decisions and at every stage of a project; Have a social impact by improving the service provided to users. - The French National Cancer Institute also coordinates a “Club of Companies” signatories of a good practice cancer & work charter (11 engagements) to support them in its implementation (covering more than 1.6 million workers). Through the Club, the companies get sensibilization sessions, often with communications from researchers, and have the opportunity to exchange their best practices with other signatory companies. Certain companies, as per Sanofi in France, are building internal networks between employees in order to facilitate discussion and anticipation of needs for employees facing cancer, as well as coordination between employee–manager-HR department.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not	

exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	Mostly consultations via digital survey or interviews.
[3. Patient Advisory Boards]	Yes
	Different kind of patient advisory board exist across France, the French National Cancer Institute "Health Democracy Committee" is detailed in the survey.
[4. Community Workshops and Forums]	Yes
	The Living Lab of the French National Cancer institute is detailed in the survey.
[5. Online Platforms and Surveys]	Yes
	Mostly consultations via digital survey or interviews.
[6. Collaborative Research Projects]	Yes
	Some training programs are developed by university hospitals regarding patient partnership and collaborative research.
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	

[There are general training/educational programmes with specific reference to cancer]	Yes
	Some training programs are developed by university hospitals regarding patient partnership and collaborative research. As well as university degree / certificate for patient expert training in oncology.
[There are cancer-specific educational materials]	Yes
	A good example is the "Universités des Patient.e.s" organised by La Sorbonne. There is a specific diploma on cancer: https://universitedespatients-sorbonne.fr/diplome/mission-patient-partenaire-et-referent-en-retablissement-en-cancerologie/
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	

[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	The "Université des Patient.e.s" initiatives also offers programmes for representatives of the healthcare system: https://universitedespatients-sorbonne.fr/diplome/mission-patient-partenaire-et-referent-en-retablissement-en-cancerologie/
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please	Yes

specify whether in health or cancer specifically]	
	Most of regulatory are framework are internal guidelines / procedures dedicated to each institution thus terminologies may differ.
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	National associations of users of the healthcare system are regulated under Article L. 1114-1 of the French Public Health Code.
[Other, please specify]	Yes
	For the French National Cancer Institute's Health Democracy Committee, 28 candidates (14 users and 14 professionals) are pre-selected by the selection committee, by examining their curriculum vitae and application file. They are expected to demonstrate their cancer-related experience(s), their ability to go beyond their individual experience in favour of a collective vision, and their motivation to become fully involved. For people applying in their own name for the users' panel, an experience within an association, a blog, a media, a community, complementary to the individual story related to the disease, will be examined. As they will be required to express themselves in a collective situation, they should have a

	certain ease in speaking out. The aim is to achieve a balance in terms of the profiles sought, gender parity and geographical representation. Candidates are informed of their pre-selection and asked to complete and sign a Public Declaration of Interests (PDI) within two weeks of being shortlisted.
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	Most of regulatory are framework are internal guidelines / procedures dedicated to each institution thus terminologies may differ.
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	National associations of users of the healthcare system are regulated under Article L. 1114-1 of the French Public Health Code.

[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	Yes
	It depends on each institutions / sponsors. Difficult for patient to receive a financial retribution if they receive allowances due to their conditions. For those who can receive financial incentives, they usually receive a travel funds as well as payment for time spent on task (review of projects, etc.).
[There is funding for patient organisations - please specify]	Yes
	The French government supports patient organisations via grants and subsidies.
[Other, please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	The French National Cancer Institute (INCa) exhibits commendable practices in citizen engagement through various initiatives and platforms. The Health Democracy Committee, comprising representatives from diverse backgrounds, ensures that the voices

	and perspectives of cancer patients, healthcare professionals, and caregivers are integrated into decision-making processes. By facilitating dialogue and consultation initiatives like those on breast cancer screening and the ten-year cancer combat strategy, INCa promotes transparency and inclusivity, enriching its strategies with real-world insights. Furthermore, INCa's creation of a Health Democracy mission and the establishment of the Living Lab signify a proactive approach towards fostering innovation and responsiveness in cancer care. The Living Lab serves as a collaborative space where stakeholders, especially patients, actively participate in the co-creation of solutions tailored to their needs. This emphasis on patient-centric approaches not only enhances the relevance and effectiveness of interventions but also fosters a sense of empowerment and ownership among stakeholders. Moreover, INCa's coordination of the Club of Companies and the Club Collectivités underscores its commitment to engaging diverse stakeholders, including private enterprises and local authorities, in the fight against cancer. By providing resources, expertise, and networking opportunities, these clubs facilitate knowledge exchange, capacity-building, and collaborative action at both organizational and community levels. Overall, these practices demonstrate INCa's holistic and inclusive approach to cancer care,

	promoting collaboration, innovation, and empowerment among stakeholders to address the multifaceted challenges of cancer prevention and treatment effectively. The Club Collectivités mobilizes local authorities for targeted cancer prevention efforts. Serving as a platform for knowledge exchange and collaboration, the club empowers municipalities and regional governments to develop tailored interventions. Through its activities, including interactive exchanges, lobbying, resource provision, and support, the Club Collectivités fosters peer-to-peer cooperation and solidarity among diverse stakeholders. By enabling local authorities to take proactive steps in addressing cancer challenges within their communities, INCa's inclusive approach ensures effective grassroots involvement in the fight against cancer.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made	No

publicly visible - please specify whether in health or cancer specifically]	
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	Yes
	Not an easy task, it really depends on which type of project they are involved in. If they participate to the elaboration of a 10yr policy, it will be difficult to attribute each participation to a part of the policy. Publication should mention on which step citizens were involved and how many were there (individual or collective perspective?).
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
	Ongoing but not yet.
[Other, please specify]	

	France Strategy published a paper about it (see below). https://www.strategie.gouv.fr/publications/peau-de-levaluateur-lecons-dune-experience-devaluation-participative
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	Additionally, to the extensive answers provided in other questions of this survey, enhancing citizen engagement in cancer requires multifaceted strategies that empower individuals to actively participate in the fight against this disease. One pivotal recommendation is to provide comprehensive training on fostering collaboration with citizens, elucidating the conditions necessary for success. Every project manager, scientist, or individual seeking to involve citizens must adhere to a holistic approach, encompassing all stakeholders in a 360-degree manner. This entails not only engaging citizens but also fostering partnerships with healthcare professionals, policymakers, and advocacy groups. By embracing inclusivity and transparency, we can cultivate a collaborative environment where citizens feel valued and empowered to contribute meaningfully to cancer initiatives.

Germany

Survey response	
Response ID	27
Date submitted	14.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Germany
[Which institution are you representing ?]	Federal Ministry for Education and Research (BMBF)
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Internal feedback loops between DLR-PT colleagues and BMBF
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	e.g. Cancer Information Service (https://www.krebsinformationsdienst.de/) and https://www.fragdiepatienten.de/ of the German Centre for Cancer Research (DKFZ)
[Healthcare Providers and Clinics]	Yes

	Some comprehensive cancer centres have trained and hired experts for this (e.g. UKE). National Centres for Tumour Diseases installed patient advisory boards
[Community Events and Workshops]	Yes
	Self-help landscape offers a variety of decentralized opportunities for workshops and events
[Social media and Online Platforms]	Yes
	See above. Self-help organisations are also active on social media etc., NDK: www.dekade-gegen-krebs.de
[Printed Materials and Brochures]	Yes
	Occasionally and usually on special occasions (World Cancer Day, etc.), information is provided in national newspapers. However, there are a number of mostly entity-related print media such as MammaMia! (breast, cervix and ovarian cancer, https://mammamia-online.de/)
[Local News and Media]	Yes
	Occasionally and usually on special occasions (World Cancer Day, etc.), see above.
[Patient Support Organizations]	Yes
	In Germany, we have a large self-help community in the field of cancer, which

	is very active (e.g. sarcomas, https://www.sarkome.de/); National Centres for Tumour Diseases have installed a patient- expert academy (https://www.patienten-experten.academy/index.php/de/)
[Government Campaigns]	Yes
	The NDK is a joint initiative between the BMBF and all relevant stakeholders active in the field of cancer research and cancer care. The goal of this 10-year programme is to improve the prevention, diagnosis and treatment of cancer by engaging various interest groups (researchers, regulators, patients, and their relatives) in the initiative.
[Educational Institutions and Schools]	Yes
	In the 16 federal states, the German school system is organized on a federal basis – not nation wide. Various stakeholders from the cancer field (German Cancer Society, DKFZ, etc.) offer formats on cancer prevention topics for schools (smoking, alcohol, UV-radiation). However, there is no nationwide curriculum on cancer in schools.
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No

[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	The accessibility and clarity of communication vary and therefore it is hard to make a general statement.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
[Other]	Additional comment: Diversity in patient engagement is a topic that will be put on the agenda. This includes modes of communication, language barriers and accessibility of information and activities.
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	There are a variety of ways to organize yourself in patient advocacy and self-help. These are organized locally, communally, regionally and nation-wide. Since the NDK and the associated expansion of the NCTs, patient participation in the field of cancer research has received a further boost. Patient advisory boards have been installed and consolidated, and PEAK has been established for further training and networking of patients and patient

	representatives. Overall, patient participation, which includes citizen participation, is an important pillar of the NDK. An Alliance for Patient Participation was founded (https://www.dekade-gegen-krebs.de/de/wir-ueber-uns/aktuelles-aus-der-dekade/_documents/allianz-fuer-patientenbeteiligung/allianz-fuer-patientenbeteiligung.html) and guidelines for successful patient participation were issued as part of the German European Council Presidency (https://www.gesundheitsforschung-bmbf.de/files/2021_06_01_Principles_Paper_bf.pdf). As part of the NDK, patient representatives/citizens are also involved in the assessment of BMBF funding measures for research funding by the BMBF; patient representatives are also represented in the committees and working groups of the NDK. Numerous patient representatives can also be found in the NDK's circle of supporters. Patient participation was also a very prominent topic at this year's German Cancer Congress.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	Consultation takes place on several levels: within the NDK patients/citizens

	are part of the Steering Committee. Consultation also takes place decentral in the various scientific institutions and ministries.
[3. Patient Advisory Boards]	Yes
	We have patient advisory boards in many clinical facilities such as university hospitals, NCT or CCCs. Driven by the NDK, the topic is currently on the upswing and more and more patient and citizen advisory boards are being set up.
[4. Community Workshops and Forums]	Yes
	In Germany, there is a very active cancer self-help scene that offers such formats.
[5. Online Platforms and Surveys]	Yes
	With the expansion of the NCT, a Patient Expert Academy (PEAK) was also established with the aim of promoting the exchange and further training of patient representatives. It also uses online platforms for this purpose. We also have the DKFZ's Cancer Information Service and a website (fragdiepatienten.de), which provides comprehensive information on cancer for citizens and patients.
[6. Collaborative Research Projects]	Yes
	As a result of the National Decade Against Cancer, it is a declared standard that patient representatives/citizens are

	involved in as many steps of BMBF-funded cancer research projects as possible.
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are general training/educational programmes without specific reference to cancer]	Yes
	There are decentralized formats within the patient organizations/self-help groups. In addition, there are training formats by experts for patient representatives/citizens/ individuals affected by cancer as part of the NCTs PEAK. Some comprehensive cancer centres have their own training formats for this (e.g. UKE). There are BMBF formats that are offered via service providers such as the DLR-PT.
[There are general training/educational programmes without specific reference to cancer]	Yes
	EUPATI offers training courses aimed in particular at industry representatives. EUPATI Essentials - EUPATI Researchers: IQIB/QUEST offer training for researchers. Further training formats are currently being developed in the

	research institutions, e.g. https://www.uniklinikum-jena.de/allgemeinmedizin/Forschung/Laufende+Projekte/Pat_in_Fo-p-904.html
[There are educational materials without specific reference to cancer]	Yes
	For clinical researchers, for example, there is a groundbreaking publication on the involvement of patient representatives from 2023 (only German language: https://zenodo.org/records/7908077)
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No

[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	In the Federal Republic of Germany, a distinction is made between formal and informal citizen participation. With regard to topics and issues concerning the National Decade Against Cancer, one can only assume informal citizen participation, for which there is no legal regulation. With regard to the measures of the Federal Joint Committee (G-BA), there is a legal regulation set out in§140f SGB V and §140f SGB V, respectively.
[Other, please specify]	No

Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	Yes
	Research projects funded by the BMBF within the NDK are encouraged to involve patients/citizens in research at as many levels as possible. Funding can also be applied for (travel, jobs, training, etc.). This is also common practice in most other health-related BMBF funding measures.

[Other, please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	As part of the German Presidency of the Council of the European Union, the German Federal Government issued a joint declaration on "Principles of Successful Patient Involvement in Cancer Research". The paper combines the views of patient organizations, cancer research, participatory research, medical and healthcare professions, industry, research management, funding organizations and the policy-making level. The paper presents a shared vision, Strategy, level and timing of involvement, Communication, understanding and relationships, Resources, knowledge and skills, Methods and approaches and Ethical and legal aspects present the collated principles in detail. (https://www.gesundheitsforschung-bmbf.de/files/2021_06_01_Principles_Paper_bf.pdf). It is considered useful because it represents a (target) standard and is a good compass for implementing patient involvement. There are also working papers from the Health Research Forum (not exclusively for cancer, in German language only): https://projekttraeger.dlr.de/media/gesundheit/GF/Forum-GF_Erkl%C3%A4rung-

	Patientenbeteiligung_27-03-2023.pdf; https://projekttraeger.dlr.de/media/gesundheit/GF/Forum-GF_Beispielsammlung-Patientenbeteiligung_03-2023.pdf
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	Yes

	We have no knowledge about such mechanisms on transparency.
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	Yes
	As patient involvement is an essential part of the NCT concept, its integration is assessed as part of the regular evaluation. The inclusion of the patient/citizen perspective is increasingly becoming the standard for BMBF funding measures and, in some cases, for cancer-related foundations, and is a criterion in the evaluation of funding applications
[No]	No
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	The NDK has done much to emphasize the importance of patient/community involvement. The central involvement of representatives in the Steering Committee and working groups was able to place important concerns in the right places. By placing the topic at large institutions such as the NCTs, the importance was additionally underlined and connecting structures for decentralized self-help were created.

Hrvatska

Survey response	
Response ID	45
Date submitted	18.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Hrvatska
[Which institution are you representing ?]	Koalicija udruga u zdravstvu (Coalition of Associations in Healthcare)
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Based on the communication with member associations
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Patient Organisation
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	National Institute for Public Health provides all the relevant information on cancer screening, and data form the National Cancer Registry every year with 2-year delay. They also have campaigns on national television and social media. Ministry of health is publishing the information regarding the policy in

	cancer care and plans for delivering cancer care.
[Healthcare Providers and Clinics]	Yes
	Healthcare providers have webpages with relevant data on employees, types of diagnostic and curative procedures they are providing, waiting lists, and the supportive care.
[Community Events and Workshops]	Yes
	More often organized in bigger cities, in other areas usually for national, European and global awareness days.
[Social media and Online Platforms]	Yes
	Activities more used by patient organizations and private healthcare providers.
[Printed Materials and Brochures]	Yes
	Patient organizations with the support of pharma companies.
[Local News and Media]	Yes
	All stakeholders, according to the awareness days, problems in delivery of cancer care or major breakthroughs.
[Patient Support Organizations]	Yes
	Providing information and building awareness trough social media,

	dedicated webpages, printed materials and public health actions.
[Government Campaigns]	Yes
	In majority, about the existing and new screening programs.
[Educational Institutions and Schools]	Yes
	Not as a part of curriculum, just by interest, and in collaboration with patient organizations and HCP organizations.
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	All that information is existing and is relevant, but it is not aimed at different age groups, not developed to the level of information or ability to access the information.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No

What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	National screening programs: breast cancer on a national level, colorectal cancer on a national level, cervical cancer on the local level (pilot), lung cancer on a national level, melanoma cancer on a national level, prostate cancer on a local level (pilot). Mostly they are built and presented by the national institute of public health, some of them in collaboration with local public health institutes, or some in collaboration with HCP professional organizations. Ministry of health is publishing the policy papers and the plans for delivery of healthcare services. Patient organizations are the one who are mostly organizing public events, provide accessible and understandable information for patients and share them over media, social media, printed materials, outreach to schools and public health events and campaigns.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	Yes
[2. Consultation]	No
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	No

	Yes
[5. Online Platforms and Surveys]	Often dome by patient organizations.
	Yes
[6. Collaborative Research Projects]	Collaborativ research project are a new format and it's just developing in Croatia
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	Yes
	Developed by patient organisations, education of the patients and caregivers, education on policy in healthcare, and different patient empowerment programs.
[There are cancer-specific educational materials]	Yes
	Developed by patient and HCP organizations and Institute for Public Health.
[There are general training/educational programmes without specific reference to cancer]	Yes
	Organized by patient organizations and HCP's.

[There are educational materials without specific reference to cancer]	Yes
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	Yes
[There are cancer-specific educational materials]	Yes
	To both answers; papers, stories and experience of patients and carers.
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	

[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	The legal framework in healthcare describes and determines the involvement of different stakeholders in healthcare in general, non-specific to cancer.
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No

[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	As per previous question. Citizens can also participate in public consultations on cancer and healthcare in general on dedicated online services.
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	There are sources of funding through public calls for proposals for engagement in general in healthcare, more specific in private profit sector.
[There is funding for patient organisations - please specify]	No
	There are sources of funding through public calls for proposals for engagement in general in healthcare, more specific in private profit sector.
[Other – please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Engagement of cancer patient organization in making and adopting of the National cancer Plan. However, they

	are excluded form monitoring and assessing the implementation of the document. The national law on healthcare predicts that a Board of Croatian health Insurance Fund has two representatives of the insured people, at the moment representatives of patients and patient organizations are excluded.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	Yes
	Public consultations online on laws and other documents in healthcare.
[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	Yes
	Public consultations online
[There is accessible information on whether public input was considered in decision making process]	Yes
	Public consultations online
[There are platforms for public feedback, such as websites that allow	Yes

for public online feedback, please specify format and whether in health or cancer specifically]	
	Public consultations online
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
	Not systematically. There are some reports of patient organizations in their inner documents.
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	More available and adequate information adapted to age, gender, education and the channels of information they use. There is an urgent need to educate children in schools on health and healthcare, as a mean of reaching the broader population. Also, there could be more engagement form GP's for their patients. The institutions of the state should include patients, citizens and other interested public in creation and implementations of

	strategies and important documents in healthcare and cancer care, because the real needs of citizens/patients are not being heard.

Ireland

Survey response	
Response ID	58
Date submitted	02.04.2024
Please include the following information:	
[Which country are you completing this survey for?]	Ireland
[Which institution are you representing ?]	HSE-NCCP and AICRI
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Collecting written answers from the National Cancer Research Group members
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Other
[Other]	Minister of Health, Patient organisation, civil society organisation
[Public Health Websites and Portals]	Yes
	https://irishcancerpreventionnetwork.com/; https://breakthroughcancerresearch.ie/; https://mariekeating.ie/; https://www.cancer.ie/; https://www.gov.ie/en/organisation-information/1942d8-cancer-patient-advisory-committee/

[Healthcare Providers and Clinics]	No
[Community Events and Workshops]	No
[Social media and Online Platforms]	Yes
	Same as above
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organisations]	Yes
	https://www.egmcancersupport.com/; https://www.cancer.ie/cancer-information-and-support/cancer-support/find-support/local-cancer-support-centres
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Government Campaigns]	Yes
	https://www.gov.ie/en/campaigns/healthy-ireland/; https://www.hse.ie/eng/services/list/5/cancer/; https://www.gov.ie/en/organisation-information/1942d8-cancer-patient-advisory-committee/
[Educational Institutions and Schools]	Yes
	Patient Voice in Cancer Research (PVCR) based in University College Dublin in line 17 under Educational

	Institutions and Schools: https://www.ucd.ie/patientvoicecancer/
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	Additional language options could be used; the ministry tries to reach different population groups through engaging with community support centres, local libraries, minority advocacy groups, treatment centres. / Needs to be available in more languages, simplified, and available in more formats including infographics for low literacy populations. More cooperation between organisations to give a unified message.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	Yes
[5. There is significant room for improvement.]	Yes
	More formats, languages, formats, with simplified messages, and more platforms required. A unified message and a collaboration of different organisations doing the same thing would be beneficial. / Needs to be

	available in more languages, simplified, and available in more formats including infographics for low literacy populations. More cooperation between organisations to give a unified message.
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Civil society organisation said: Within their organization, they use all of the examples listed below to bring messages of cancer prevention, risk reduction and symptom awareness. They also co-founded the Irish Cancer Prevention Network with other cancer charities and governmental organisations and policy makers and use each of these methods to explain cancer research – need, processes, findings and impacts. The Department of Health (ministry): DoH established a Cancer Patient Advisory Committee. This committee welcomes members from across the country and seeks to have a broad representation in terms of geographic location, age, gender, cancer types. Members are primarily cancer patients and sometimes family members of or advocates for cancer patients.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No

[2. Consultation]	Yes
	Public consultation is invited when new national cancer strategies are being developed. Annual consultation is sought by the screening advisory council.
[3. Patient Advisory Boards]	Yes
	The Department of Health (Ministry) hosts the Cancer Patient Advisory Committee.
[4. Community Workshops and Forums]	Yes
	Health Research Charities Ireland and Health Research Board funding scheme: https://hrci.ie/irish-health-research-forum/
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	Yes
	Irish Research Council (IRC), Health Research Board (HRB), Irish Cancer Society (ICS), Breakthrough Cancer Research, Irish Association for Cancer Research (IACR)
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	Yes

	A National Public Patient Involvement (PPI) Ignite, and IPOSSI, some charities, including Breakthrough Cancer Research run their own educational and training programmes for interested citizens and citizens impacted by cancer. Patient Voice in Cancer.
[There are cancer-specific educational materials]	Yes
	Generated by multiple agencies, including the Health Service Executive and Cancer Charities.
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	The Voice Programme
[Other comment]	Branch of Independent Patient Voice
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	Yes

	https://ipposi.ie/; www.mariekeating.ie; https://ppinetwork.ie; Marie Keating Foundation
[There are cancer-specific educational materials]	Yes
	Provided by civil society organisations, patient organisations and Health Service Executive's National Cancer Control Programme (HSE)-NCCP
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	The National Cancer Strategy makes reference to who can represent citizens

	as part of the Cancer Patient Advisory Committee only.
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	Charity Regulator https://www.charitiesregulator.ie/
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place – it is not formally defined who can represent citizens]	Yes
	There are organisational level governance structures in place to govern and safeguard citizen engagement.
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests – please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens’ interests – please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes

	There are organisational level governance structures in place to govern and safeguard citizen engagement.
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	Yes
	The Irish Research Council contributes funds to The PPI Ignite network which promotes excellence and inspires innovation in public and patient involvement (PPI) in health and social care research in Ireland. This is in collaboration with the Health Research Board (HRB).
[There is funding for patient organisations – please specify]	No
[Other – please specify]	Yes
	There are organisational level governance structures in place to govern reimbursement, however, the HRCI and PPI Ignite are working to standardise this. www.hrci.ie; https://ppinetwork.ie/
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Ireland is advancing well to include citizen engagement in a meaningful

	way in cancer care and research. Continued collaboration is important (HRCI, PPI Ignite, NCCP) but some national guidelines on reimbursement and recognition of the role and expertise played by charities in this could be increased.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	Yes
	Citizens – not necessarily cancer specific Assembly. / The Cancer Patient Advisory Committee meeting minutes are published publicly; when consultation is sought from citizens on policy, consultation documents are published where appropriate.
[There is accessible information on whether public input was considered in decision making process]	Yes
	Organisational-specific

[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	Yes
	Cancer Strategy
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	Yes
	This is an ongoing conversation and was the focus of the Irish Health Research Forum last year, as well as the PPI Ignite and individual organisations.
[No]	No
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	Ireland is advancing well to include citizen engagement in a meaningful way in cancer care and research. Continuing collaboration is important (HRCI (Health Research Charities Ireland), PPI Ignite (Public and Patient Involvement in health and social care research), NCCP (National Cancer Control Programme)) but some national guidelines on reimbursement and

	recognition of the role and expertise played by charities in this could be increased.

Italy

Survey response	
Response ID	55
Date submitted	26.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	55
[Which institution are you representing ?]	45377
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	meeting
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Academic or Research Institution
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://www.salute.gov.it/portale/tumori/homeTumori.jsp; www.frrb.it; www.epicentro.iss.it
[Healthcare Providers and Clinics]	Yes

	www.istitutotumori.mi.it
[Community Events and Workshops]	No
[Social media and Online Platforms]	Yes
	https://salute.regione.emilia-romagna.it/agenda/regione/201cengaging-patients-for-patient-safety201d-coinvolgimento-dei-pazienti-e-dei-cittadini-nella-sicurezza-delle-cure
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organizations]	Yes
	www.alleanzacontroilcancro.it; www.fondazionethebridge.it; www.cittadinanzattiva.it
[Government Campaigns]	Yes
	www.salute.gov.it
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	Yes

	the Italian landscape is very fragmented thus we have provided some relevant examples
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Intervention in favour of citizen engagement is mainly limited at local/regional level (single health care providers, local health authorities, regional campaigns). National activities are implemented by organisations like Ministero della Salute, Alleanza contro il cancro and Istituto Superiore di Sanità. Broader initiatives are built on European funded projects within or out of the Cancer Mission.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	Involvement of patient representative in expert panels (public/private funded projects)
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes

	This is the most frequent activity at regional level.
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	Yes
	Collaborative projects where patients are engaged since project inception both in research or dissemination activities.
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes
	according to our knowledge there no specific training programmes targeting citizen engagement
[There are no corresponding educational materials]	No

What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes
	according to our knowledge there no specific training programmes targeting citizen engagement
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No

[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	We are not aware of any regulation for patient engagement in health
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	We are not aware of any regulation for patient engagement in health
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	Yes

	European funded programmes including National Resilience and Recovery Plan
[There is funding for patient organisations – please specify]	Yes
	National and European funding programmes
[Other – please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Some processes are on-going thanks to activities in the frame of EU funded projects.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	No

[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	Yes
	We are not aware of such mechanisms
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	No
[Other, please specify]	Yes
	We are not aware of such monitoring at national level. Each organisation has its own monitoring mechanisms.
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	The future NCMH should provide single entry point to enhance citizen engagement in cancer for patients, care givers, institutions and health providers

Latvia

Survey response	
Response ID	48
Date submitted	20.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Latvia
[Which institution are you representing ?]	Riga East University Hospital
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	on meeting basis
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Patient Organisation
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://www.spkc.gov.lv/lv/informacija-iedzivotajiem-par-cpv
[Healthcare Providers and Clinics]	Yes

	https://aslimnica.lv/kruts-veselibas-centrs/kruts-vezis/
[Community Events and Workshops]	Yes
	We have started to work on it, first online discussion was held regarding breast cancer pathway in Facebook. https://www.facebook.com/watch/live/?ref=watch_permalink&v=293480066188945
[Social media and Online Platforms]	Yes
	https://www.facebook.com/watch/live/?ref=watch_permalink&v=293480066188945; https://www.facebook.com/reel/331949289541147
[Printed Materials and Brochures]	Yes
[Local News and Media]	Yes
	https://station.lv/#53213203
[Patient Support Organisations]	Yes
	https://onkoalianse.lv/lv/
[Government Campaigns]	Yes
	https://www.spkc.gov.lv/lv/kampanas
[Educational Institutions and Schools]	Yes
	Sometimes, not on regular basis

Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	Yes
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Unfortunately, there are a little activities / initiatives regarding citizen engagement. Riga East University Hospital meets with oncology patients' organizations every 6 months for different cancer related questions. Usually, the engagement method is Consultation. The discussions and meetings are organized. For example, when Breast Cancer patient pathway was developed, online discussion has been organized with citizens.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	

[1. Citizens' Council]	No
[2. Consultation]	Yes
	face-to-face and remote meetings mostly
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	No
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	No
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes
[There are no corresponding educational materials]	Yes

	There is a need to educate government first on the topic of citizen engagement.
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	Yes
	There is a need to educate government first on the topic of citizen engagement.
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
	At the moment Patients organizations are representing citizens, but it is not regulated

[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	No

[There is funding for patient organisations – please specify]	No
[Other – please specify]	Yes
	There is not available funding for patient organisations
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	We don't have much. Some discussions have happened, these were good practices, as citizens' voices were heard, however there was not big engagement. There also have been held questionnaires, but also not big engagement from citizen side. Perhaps more beneficial would be workshops, focus groups, etc. when face-to-face meetings are held.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/ opinion on a law regarding proposed laws is made	No

publicly visible – please specify whether in health or cancer specifically]	
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	The creation of HUB with shared responsibilities would be beneficial supported by regulations and funding from Europe. At the moment there is nobody responsible for citizen engagement, therefore, this area is not developed. Nobody takes care of it 100%.

Luxembourg

Survey response	
Response ID	59
Date submitted	02.04.2024
Please include the following information:	
[Which country are you completing this survey for?]	Luxembourg
[Which institution are you representing ?]	Institut National du Cancer (INC)
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	through meetings
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Academic or Research Institution
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	Fédération des Hôpitaux Luxembourgeois (FHL, https://fhlux.lu/web/evenements/journee-nationale-du-patient-partenaire/), Luxembourg Institute of Health (LIH, https://www.lih.lu/en/ppi/), Institut National du Cancer (https://institutnationalducancer.lu/jepa

	rticipe/), University of Luxembourg – Competence Center
[Healthcare Providers and Clinics]	No
[Community Events and Workshops]	Yes
	Exchange workshop organised with patients in March 2024 on the theme of the diagnosis communication (collaboration National Cancer Institute (INC), Luxembourg Institute of Health (LIH), Fédération des Hôpitaux Luxembourgeois (FHL) and National Cancer Plan (PNC2)) / All Patient and Public involvement (PPI) initiative led by the LIH, which includes regular meetings, trainings and workshops for patients on various themes / Organisation of the Healthcare Week, annual conference gathering the whole healthcare sector in Luxembourg, and discussing on patient-centred aspects among various other topics (https://www.hwl.lu/en/)
[Social media and Online Platforms]	Yes
	All social medias of the above-mentioned institutions (LinkedIn, Facebook, Instagram)
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organizations]	No
[Government Campaigns]	No

[Educational Institutions and Schools]	Yes
	University of Luxembourg – Competence Center
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	In Luxembourg, information for the public is available in several languages (usually 4: FR, DE, EN, PT) and is simple and accessible.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	In addition to initiatives aimed at the general population (Relais pour la Vie, etc.), patient-partner initiatives have become increasingly common in Luxembourg over the past 2 years, particularly at the LIH but also in the national hospitals and treatment centres.

What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	Several patient-partners initiatives led by the LIH (with a focus on research), and the FHL (with a focus on care) / Workshop organised with patients to improve the diagnosis communication.
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes
	Idem
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	Yes
	PPI initiative existing at the LIH (research-centred)
[Other]	Patients in ethics
	Ethics committees in Luxembourg (national and hospital-based) include patients representatives.

What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?

[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	Yes
	General training to explain the concept of PPI, and why this is important / training for researchers on how patients and general population can be involved in different steps of research
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	Patient-partner pilot training
	In addition, we are currently developing a national pilot training on patient-partner to explain the overall concepts and existing ways to encourage the collaboration between patients and healthcare professionals (i.e. clinicians, nurses, researchers, ...). The training is organised for pairs of patient & healthcare professional, which have identified a specific project to work on. This pilot training is being developed

	under the collaboration between the University of Luxembourg – Competence Center, the LIH, the FHL and the national association of patients organisations (CAPAT, not specific to cancer)
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	Various trainings
[Other]	EUPATI training dedicated to researchers to explain the concept of PPI and the added value of PPI in research / pilot training in preparation for patient-partners (see details above)

Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No

[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	No
[Other – please specify]	Yes
	The existing initiatives are all institution-driven, without specific funding
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	/
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	No

[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	- Create regular national information workshops to inform citizens that involvement in research and care (throughout the whole patient journey) is available and possible – Elaborate and provide further trainings for citizen, researchers and healthcare professionals on the PPI concepts – Take into account the profile of citizens: citizen, relative, patient, patient-expert

Malta

Survey response	
Response ID	31
Date submitted	15.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Malta
[Which institution are you representing ?]	Ministry for Health and Active Ageing
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	consultation with MCST
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Academic or Research Institution
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://maphm.org/
[Healthcare Providers and Clinics]	Yes
	https://healthservices.gov.mt/en/SAMOC/Pages/default.aspx

[Community Events and Workshops]	No
[Social media and Online Platforms]	No
[Printed Materials and Brochures]	No
[Local News and Media]	No
[Patient Support Organisations]	Yes
	https://www.maltahealthnetwork.org/
[Government Campaigns]	Yes
	https://hpdp.gov.mt/
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	varies by authorship. most communications are in English.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	

	Public consultation of documents such as the National Cancer Plan Involvement in different VOs concerned with cancer (e.g. patient groups, fund-raising groups, service providers e.g. Hospice Malta) Specific events Patient representatives on governmental committees
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	No
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are general training/educational programmes without specific reference to cancer]	Yes

	https://healthservices.gov.mt/en/SAMOC/Pages/SAMOC-TICC-Publications.aspx
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	Yes
	https://hpdp.gov.mt/hpu
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes

[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests -	No

please specify whether in health or in cancer specifically]	
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	No
[Other, please specify]	Yes
	There is no relevant funding
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No

[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
	Yes
[No]	No

Netherlands

Survey response	
Response ID	40
Date submitted	15.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Netherlands
[Which institution are you representing ?]	IKNL
[How did you collect and consolidate your answers (e.g., on the basis of a	by search of policy documents and web search, combined with knowledge from IKNL and partners

workshop or meeting, by collecting written answers...)?]	
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Patient Organisation
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	The web portal with information about all cancer types, advice about how to communicate with health professionals and, announcing many meetings and symposia for patients is https://www.kanker.nl/
[Healthcare Providers and Clinics]	Yes
	Expert hospitals organize meetings on rare cancers, e.g.: https://www.avl.nl/agenda/2024/patientenbijeenkomst-zeldzame-kankers/#:~:text=9%20mrt.,250)%20is%2086%25%20zeldzaam. And many hospitals and regional networks of hospitals organize meetings and lectures for patients and their loved ones.
[Community Events and Workshops]	Yes
	Yes, many IPSO centre for living with cancer organize events. for instance:

	https://oriolus-achterhoek.nl/jongvolwassen/
[Social media and Online Platforms]	Yes
	All activities for patients and their loved ones can be found on the web portal Kanker.nl: https://www.kanker.nl/agenda Many activities are posted on social media by patient organisations, hospitals and others.
[Printed Materials and Brochures]	Yes
	All leaflets can be ordered on the portal Kanker.nl. Mainly health professionals order the leaflets here to distribute them to their patients: https://www.kanker.nl/zorgprofessionals
[Local News and Media]	Yes
	Especially around World Cancer Day there are many events announced in local newspapers and news websites. Also, throughout the year the Centre for living with cancer organize many events which are announced in local newspapers: https://ipso.nl/ipso-centrum/
[Patient Support Organizations]	Yes
	All announcements for events of patient organisations can be find on the web portal Kanker.nl: https://www.kanker.nl/lotgenoten/bijeenkomsten-kpo

[Government Campaigns]	No
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
	Hospitals and patient organisations always try to write in plain Dutch, but there is still room for improvement. Often information is available in Dutch and English, but more rarely also translated in Turkish and Moroccan.
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Local, community, regional, national and organisational informational meetings on e.g. tumour types, AYA, lifestyle, fatigue after cancer and other survivorship issues. Many health care organisations host lectures and symposia, amongst others at and around World Cancer Day. On a local,

	community, regional and national and organisational level there are sometimes lectures on cancer and lifestyle and opportunities for prevention. There is however no national policy on these opportunities for sharing of knowledge about prevention. A smaller charity has prevention of cancer as focus, see https://www.wkof.nl/acties-en-campagnes/actie-samen-kanker-voorkomen/ The 14 cancer patient organisations are joined in the Netherlands Federation of Cancer Patient Organisations, https://nfk.nl/ Patients and their loved ones can join a patient organisation and attend their meetings and yearly symposia. The NCMH has organised 4 meeting from 2023 where representatives of patient organisations were invited amongst many others to discuss about the national cancer plan.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	The NCMH has organised 4 meeting from 2023 where representatives of patient organisations were invited amongst many others to discuss about the national cancer plan.

[3. Patient Advisory Boards]	Yes
	All hospitals are obliged by law to have a patient advisory board. Also, the Netherlands Comprehensive Cancer Organisation, the national knowledge institute hosting the Netherlands Cancer Registry has a patient advisory board.
[4. Community Workshops and Forums]	Yes
	IPSO centre for living with cancer and the 21 cancer patient organisations organise many workshops and forums
[5. Online Platforms and Surveys]	Yes
	www.kanker.nl hosts online forums and surveys. Also, the Netherlands Federation of Cancer Patient Organisations has a regular survey on topics of cancer care and survivorship. They publish the outcomes, talk to journalists about it and use is for agenda setting and public affairs on these topics.
[6. Collaborative Research Projects]	Yes
	There are many collaborative research projects. The largest funder of cancer research, the KWF, hold policy on collaborating with patients in all their funded research: https://www.kwf.nl/onderzoek/kwf-programma-onderzoek-implementatie/patientenparticipatie

	For an example see this study on AYA: https://www.compraya.nl/
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	Yes
	There are some training programmes aimed specifically on how to inform and involve migrant groups and migrant cancer patients. E.g.: https://www.voorlichtersgezondheid.nl/gezondheidsvoorlichting-2/kanker/
[There are cancer-specific educational materials]	Yes
	Some toolkits with educational materials for migrant groups, created by the Dutch expertise centre for literacy, called Pharos: and https://www.pharos.nl/kennisbank/toolkit-voorlichtingen-aan-migranten-over-kanker/
[There are general training/educational programmes without specific reference to cancer]	Yes
	There are some training programs for health professionals about how to involve patients, e.g. https://www.nivel.nl/nl/publicatie/patienttime-participatory-development-and-evaluation-web-based-pre-visit-

	communication Many are developed in the course of a research project, summaries of some of the research can be found at the Netherlands Association for Psychosocial Oncology (NVPO): https://nvpo.nl/kennishub/?_thema=communicatie-patienteninformatie
[There are educational materials without specific reference to cancer]	Yes
	PGO support offers training courses, leaflets and web info for patient representatives who want to participate in policy making or scientific research
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	Some cancer patient organisations offer educational materials, e.g. on their webpages.
[There are general training/educational programmes without specific reference to cancer]	Yes

	There are some training programs for professionals about involving patients and enhancing patient participation, these are not cancer specific: https://hetlsr.nl/evenementen/verdiepingscursus-participatie-en-achterban-2/ Also see the website of Participatiekompas: https://participatiekompas.nl/vormgeven Particpatiekompas offers training for professionals, leaflets, web info and advice.
[There are educational materials without specific reference to cancer]	Yes
	There are a lot of educational materials about citizen participation, e.g. of knowledge institite Movision, these are not cancer specific: https://www.movisie.nl/burgerparticipatie
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please	Yes

specify whether in health or cancer specifically]	
	The largest funds for scientific research hold a strong policy for patient participation, e.g. the Dutch Cancer Society KWF https://www.kwf.nl/en/programme-research-implementation/patient-participation-in-kwf For non-cancer specific information, see the website of a large governmental funding agency for scientific research Zonmw: https://www.zonmw.nl/en/participation-and-citizen-science
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	All health care providers are legally obliged to hold a Patient Advisory Board, participants can be patients, survivors, relatives or healthy citizens. See https://www.rijksoverheid.nl/onderwerpen/rechten-van-patient-en-privacy/medezeggenschap-clienten-in-de-zorg
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No

[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	On a national level a representative of the Netherlands Federation of Cancer Patient Organisations (NFK) is a full member of the National Oncology Taskforce. In policy and research projects there is often a preference for a patient representing a patient organisation to participate. The NFK has 21 allied cancer patient organisations and can often send a representative to participate in policy discussions.
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	All health care providers are legally obliged to hold a Patient Advisory Board. See https://www.rijksoverheid.nl/onderwerpen/rechten-van-patient-en-privacy/medezeggenschap-clienten-in-de-zorg
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	Yes

	In research projects and in Patient Advisory boards patients can receive a reimbursement of their costs for travel and sometimes also a financial incentive for the time spent. This is paid by the health care organisation.
[There is funding for patient organisations - please specify]	Yes
	The patient organisations are funded by both the Dutch Cancer Society and the Ministry on health. For funding opportunities with the Ministry of health, see https://www.pgosupport.nl/dossiers/patientenorganisaties/fondsenwerving/subsidie-patientenorganisaties
[Other, please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Empowering screening activities, home-base testing for HPV. Vaccination of boys and youth against HPV up to 18 years. Alcohol and tobacco publicity and selling restrictions. State promotion of active lifestyle (hiking and sporting tracks). Active Charity Fund for non-financed (by Estonian Health Insurance Fund) cancer drugs.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a	

law* statements, input by citizen representatives or any other form of public feedback or input) ?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	

	An important goal is to improve the agenda setting by patients and patient organisations. In scientific research patient organisations are consulted because it is obligatory with the funding agency. But the patient organisation then advices on a research protocol that is already written. Frequently, patients would prioritize other topics for research and would ask different research questions. Then they are consulted in a too late stage of the research proposal. With the current policy on patient participation thus patients are often consulted too late.

Norway

Survey response	
Response ID	34
Date submitted	15.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Norway
[Which institution are you representing ?]	Norwegian Cancer Society
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Meeting with key mission hub partners
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Other Research Council Norway and Oslo Cancer Cluster
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://www.helsedirektoratet.no/tema/brukermedvirkning
[Healthcare Providers and Clinics]	Yes

	https://www.helse-sorost.no/brukermedvirkning#om-brukerutvalget; https://www.helse-midt.no/om-oss/brukermedvirkning/;
[Community Events and Workshops]	No
[Social media and Online Platforms]	Yes
	https://no.linkedin.com/posts/sykehuset-ostfold-hf_vitalt-sykehuset-%C3%B8stfold-inviterer-til-folkem%C3%B8te-activity-7166395966554685441-XEqM
[Printed Materials and Brochures]	No
[Local News and Media]	Yes
	https://www.nrk.no/buskerud/kreftbehandlinga-ved-nye-drammen-sjukehus-blir-betre-_-kan-mellom-anna-tilby-stralebehandling-1.16609408 One example only
[Patient Support Organizations]	Yes
	https://kreftforeningen.no/tilbud/ https://kreftforeningen.no/forskning/brukermedvirkning-i-forskning/ https://kreftforeningen.no/engasjer-deg/brukerpanel/
[Government Campaigns]	No
[Educational Institutions and Schools]	No
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	

[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	Yes
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	https://kreftforeningen.no/engasjer-deg/brukerpanel/ (all cancers) Municipalities are well placed to use citizen engagement for policy development, but not specifically related to health or cancer. https://www.ks.no/fagomrader/demokrati-og-styring/innbyggermedvirkning/om-innbyggermedvirkning/kom-i-gang-med-innbyggermedvirkning/ Various citizen panels, not only for health or cancer, but could be used for this: Municipalities of Bærum https://www.baerum.kommune.no/politikk-og-samfunn/samfunnsutvikling/innbyggerpanel/ Asker https://www.asker.kommune.no/om-asker-kommune/innbyggerpanel/

What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	Data from user panels and public hearings and meetings are used as input in patient advocacy. Public hearings, for citizen and patient representatives mostlyhttps://www.regjeringen.no/no/dokument/hoyringar/id1763/?isfilteropen=True&ownerid=421&term=kreft
[3. Patient Advisory Boards]	Yes
	There are thousands of these; in hospitals, public welfare and service authorities, research and innovation projects, etc.
[4. Community Workshops and Forums]	Yes
	Mostly sporadically, as part of citizen/patient dialogue initiatives https://www.cancermission.no/arrangementer-cm/2022/folkemote-om-fremtidens-kreftomsorg-i-drammen/ (one recent example)
[5. Online Platforms and Surveys]	Yes
	User panels and citizen panels mentioned above are digital tools
[6. Collaborative Research Projects]	Yes

	Most funders will require a level of user participation in projects. https://www.cancermission.no/aktuelle-saker/2023/brukermedvirkning-i-forskning/
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc…?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	Yes: https://kreftforeningen.no/forskning/brukermedvirkning-i-forskning/ (This is for user participation in research, below also)
[There are general training/educational programmes without specific reference to cancer]	Yes
	https://www.statsforvalteren.no/siteassets/fm-rogaland/dokument-fmro/kommunereform/ks---idehefte.pdf https://www.regjeringen.no/no/tema/forskning/innsiktsartikler/veileder-og-rad-om-innbyggerinvolvering-i-forskning/id3016041/
[There are educational materials without specific reference to cancer]	Yes

	https://kurs.helse-sorost.no/ScormServices/ScoStart.aspx?load=preview&scorm_version=1.2&starting_url=/uploaded/scormcourse/grunnopplaering_V090719/scormdriver/indexAPI.html https://www.remedy-senter.no/brukermedvirkning-i-forskning Course, user participation in health research (ihelse.net). Developed by the Regional User Committee in Helse Vest and the Competence Centre for Clinical Research in Helse Vest, in collaboration with the Team for digital learning. Kursbygger (ihelse.net) Frequently asked questions about user participation in research (oslo-universitetssykehus.no). From Oslo University Hospital. Brukermedvirkning i forskning – ofte stilte spørsmål – Oslo universitetssykehus HF (oslo-universitetssykehus.no)
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No

[There are general training/educational programmes without specific reference to cancer]	Yes
	https://www.helse-sorost.no/siteassets/documents/Brukermedvirkning/Veileder---brukerrepresentanter-i-prosjekt-rad-og-utvalg_Revidert-2023.pdf
[There are educational materials without specific reference to cancer]	Yes
	https://www.helsedirektoratet.no/tema/brukermedvirkning
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes

	In health. Users have the right to participate, and the healthcare institutions have a duty to involve the user. User participation is a statutory task and gives patients and next of kin the opportunity to influence the design of health services. Legal reference: https://lovdata.no/dokument/NL/lov/1999-07-02-63
[Other, please specify]	No
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
	Very often, these consultations are done through patient organisations, rather than engaging citizens directly. They are picked out as relevant "hearing bodies", among other organisations and institutions.
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No

Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	No
[There is funding for patient organisations - please specify]	No
[Other, please specify]	Yes
[Other – please specify] [Comment]	Not that we are aware of – there is a lot of funding for supporting user participation, and patient engagement, but not citizen engagement.
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	https://www.cancermission.no/aktuelle-saker/2023/felles-kronikk-om-kreft-i-drammen/ Organisers and active contributors: Hospital: Managers, Clinicians, Municipality: Managers, Cancer coordinators, public library Cancer Society: Regional office, Cancer Mission adviser Target group – multipliers at Fjell Public Library Information: Press work – all joint channels Presentations Stands Post-Its! Open Mic with a panel on stage Press clippings: Kreftbehandlinga ved nye Drammen sjukehus blir betre – kan mellom anna tilby strålebehandling – NRK Oslo og Viken – Lokale nyheter, TV og radio https://radio.nrk.no/serie/distriktsprogra

	m-buskerud/DKBU01045823?utm_source=nrkradio&utm_medium=delelenke-ios&utm_content=prf:DKBU01045823 https://tv.nrk.no/se?v=DKOV98102523&t=447s
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	Yes
	This is not cancer specific, concerns all such proposals. Patient organisations and civil society organisations are asked to give feedback, but the govt. consultations are not open to individual citizens usually.
[There is accessible information on whether public input was considered in decision making process]	Yes
	Yes, this is an example: https://www.regjeringen.no/no/dokumenter/hoyring-forslag-til-endringar-i-helselovgivinga/id2986415/?showSvar=true&term=&page=1&isFilterOpen=true

	And here is another New National Cancer Strategy Hearing: https://www.helsedirektoratet.no/horinger/nasjonal-kreftstrategi-2024-2028
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	Yes
	No monitoring, but there is both a reflection and piloting of actions in Cancer Mission Hub Norway, both on user participation and citizen engagement
[No]	No
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	First: to treat the topic with due respect and make clear and meaningful distinctions between citizen and user/patient engagement – and who is at the receiving end of this engagement. The commission expert

	group to support the monitoring of EU missions, seem to have a different interpretation of citizens engagement activities, and list the following: • Mapping and opinion collection, actions and databases building, supported by HE calls; • Dissemination activities (identification and rewards for best practices); • Awareness actions, focus on capacity building, literacy, education with pupils, students, teachers or parents; • Networking events, such as civil society fora; citizen events; participatory workshops; national policy roundtables to elaborate national policy roadmaps; • Co-creation processes, aiming to identify priorities; develop citizen' science actions; carry out participative and co-creative methods or implement initiatives; • Creation of devoted structures, such as national support structures; Mission hubs; citizen observatories; citizen assemblies; citizen panels; citizen communities. The UN/WHO definition has a different approach: a deliberative form of public participation to inform effective policy-making by providing members of the public with a platform to discuss a policy issue. recognizing the views, perspectives and knowledge of a diverse group of people living within a particular region or country, as part of policy discussions There is untapped potential in the area of citizen engagement in cancer, but this is not the case for user participation and patient advocacy – whether in health

	care institutions or policy making, and in research and innovation projects – where there are both long lasting legal requirements and practice to involve people affected by cancer in decision making. Similarly, there is a longstanding practice of campaigns to increase health literacy from public and private organisations- which is communication with citizens, but probably falls out of the definition in this survey. There are also a vast number of arenas for patients and caregivers to receive information and exchange views on cancer related issues, organised by the Cancer Society and other patient organisations, the hospitals, and others. It is difficult to separate the shortcomings in the field of citizens dialogue when this is in the same category as user/patient participation, where the support system is well established. For this reason, we did not add any "best practice" examples on citizens engagement but look forward to an exchange on this!

Poland

Survey response	
Response ID	57
Date submitted	02.04.2024
Please include the following information:	
[Which country are you completing this survey for?]	Poland
[Which institution are you representing ?]	M.Sklodowska-Curie National Institute of Oncology in Warsaw – MSCI
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	meeting
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	we gathered the information from: Ministry of Health, Public Health Institute, Patient Organisations, Cancer Center, Academic or Research Institution
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether this information is given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	by: https://profibaza.pzh.gov.pl/node/161; ProfiBase system – is a system of digital

	provision of public information on the health situation of the population and implementation of health programmes for disease prevention and health promotion in Poland
[Healthcare Providers and Clinics]	Yes
	www.nio.gov.pl;
[Community Events and Workshops]	Yes
	https://www.pzu.pl/zdrowe-zycie; https://fop2024.pl/;
[Social media and Online Platforms]	Yes
	on social media (Twitter, LinkedIn, FB, Instagram) and online platforms (YouTube), regularly of various institutions
[Printed Materials and Brochures]	Yes
	materials on prevention programmes, pilot programmes, printed in the national, regional press. Brochures available in outpatient clinics and hospitals; https://www.nfz.gov.pl/gfx/nfz/userfiles/_public/dla_pacjenta/magazyn_ze_zdrowiem/nfz_nr_10_04-12-23_online.pdf
[Local News and Media]	Yes
	public awareness campaigns on local television and in the press, radio on pilot campaigns and prevention programmes

[Patient Support Organizations]	Yes
	https://www.zwrotnikraka.pl/category/wydarzenia/konferencje-onkologiczne/; patient organisations' websites: https://www.raknroll.pl/; https://www.sarcoma.pl/miesaki/; https://www.onkocafe.pl/; https://alivia.org.pl/; http://www.amazonkifederacja.pl etc.
[Government Campaigns]	Yes
	https://planujedlugiezycie.pl/; https://www.prezydent.pl/aktualnosci/inicjatywy/zdrowe-zycie; https://pacjent.gov.pl/
[Educational Institutions and Schools]	Yes
	https://ippez.pl/
[Other]	Congresses
	at the Health Challenges Congress, a space for debate on health challenges in Poland – https://www.hccongress.pl/2024/pl/o-wydarzeniu/305/
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No

[3. The accessibility and clarity of communication vary.]	Yes
	The materials available are written in simple language and have a good level of information content
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	Yes
	The available information is not very visible to the public and is still not sufficiently differentiated according to needs, age, education, etc. Due to the war in Ukraine and the large number of refugees, there is a need to increase the distribution of materials in Ukrainian and/or English
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	In general, we can say there is a relatively large availability of various initiatives and opportunities for citizen involvement. National: secondary prevention screening for breast, lung, and cervical cancer. At the regional level: screening for prostate cancer, prevention of liver cancer. Primary prevention – healthy eating lessons in primary schools, online PZH diet centre, nFZ diets. Activities locally: onco run and others.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not	

exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	Yes
	Patients' Council of the Patients' Rights Ombudsman, Patients' Council of the Minister of Health
[2. Consultation]	Yes
	For example, an open-door day organised by the NIO-PIB is where interested persons can find support in the form of tests and medical advice offered to encourage active cancer prevention and take advantage of the available programmes.
[3. Patient Advisory Boards]	No
[4. Community Workshops and Forums]	Yes
	Community workshops – responding to women's needs – breast self-examination and breast cancer prevention knowledge by NIO-PIB at the invitation of employees from various institutes. Are breast self-examination workshops run by patients' organisations, e.g. the Amazons association?
[5. Online Platforms and Surveys]	No
[6. Collaborative Research Projects]	No
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives,	

patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	PACJENCI.PRO Academy for the Development of Patients' Organisations is a nationwide initiative that aims to educate, share experiences and support patients' organisations to achieve their goals and increase their participation in building the health care system (https://www.pacjenci.pro/o-projekcie/) or training for patient organisations, employees of their company run by industry e.g. Sanofi.
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	

[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
	We do not have sufficient knowledge on the subject. There is certainly a need to organise training, materials preparation, etc. Perhaps, for example, the materials provided as part of the Hepatocellular Carcinoma Prevention Programme on communication with the patient and motivation of the patient to take action for prevention or treatment could be part of this. https://watrobanieboli.pzh.gov.pl/wp-content/uploads/2022/10/ulotka-informacyjna-koordynator-pacjenta.pdf, or training organised by the patient organisation Gwiazda Nadziei (Star of Hope), which organises online training for school and district coordinators of educational programmes.
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No

Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	For example, patient organisations may be authorised to represent the interests of a citizen/patient in the field of health. The legal regulations on the basis of which the list of patients' organisations is maintained are set out in the Act of 6 November 2008 on Patients' Rights and the Patients' Ombudsman (Journal of Laws of 2023, item 1545, as amended).
[Other, please specify]	Yes
	parliamentary interpellations
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No

[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	the document regulating the principles of cooperation between the Ministry of Health and organisations acting on behalf of patients is the programme of cooperation between the Ministry of Health and non-governmental organisations and entities listed in Article 3(3) of the Act of 24 April 2003 on public benefit activity and voluntary work, called "Strategy of cooperation between the Ministry of Health and patient organisations for 2023-2024". The strategy builds on the experience developed so far by patient organisations, in particular by: The Forum of Patients' Organisations at the National Health Fund, the Council of Patients' Organisations at the National Health Fund, the Council of Patients' Organisations at the Patients' Ombudsman, Dialogue for Health and the Patients' Needs Group of the Scientific Working Group at the Medical Research Agency. The Strategy sets out, among other things, the principles of cooperation of patient organisations with the Minister responsible for health

	matters and how their cooperation with the Ministry of Health is to be coordinated. The strategy identifies the key role of the Council of Patients' Organisations to the Minister in charge of Health, established by the Order of the Minister of Health of 16 March 2022 on the establishment of the Council of Patients' Organisations to the Minister in charge of Health (Dz. Urz. Min. Zdrow. poz. 32).
[Other, please specify]	patients' councils in National Hospital Framework hospitals
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens - please specify]	Yes
	e.g. reimbursable prophylactic HPV vaccination in the age group 12-14 for boys and girls – if parents register their children in the required age group, they do not have to pay for the vaccination
[There is funding for patient organisations - please specify]	Yes
	The manner of entrusting public tasks to patient organisations is carried out in accordance with the principles set out in the Act of 24 April 2003 on public benefit activity and volunteerism. Public health tasks are entrusted in accordance with the principles set out in Chapter 4 of the Act of 11 September 2015 on public health (Journal of Laws of 2022, item 1608). Entrusting the

	implementation of public tasks as commissioned tasks within the meaning of the Act of 27 August 2009 on public finance (Journal of Laws of 2022, item 1634, as amended), may take the form of: 1) entrusting the performance of public tasks, together with granting a grant for financing their implementation, or 2) supporting the performance of public tasks, together with awarding a grant for co-financing their implementation. The preferred form of commissioning or supporting the implementation of public tasks by the minister competent for health matters is an open tender. The tasks commissioned to patient organisations within the competence of the minister in charge of health include in particular, conducting training, analyses and sociological research. When assessing the possibility of ensuring high-quality of task implementation by the bidder, the bidder's previous experience in implementing tasks of a given type, the nature of the implemented actions, and their scale (nationwide/local actions) are taken into account in particular. In the case of applications for the implementation of a public task submitted on the initiative of non-governmental organisations, the bidder's previous experience in the implementation of tasks of a given type shall also be taken into account when assessing its ability to ensure high-quality of task implementation.
[Other, please specify]	No

Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	All of the following examples result from citizen involvement, including patient organisations in cooperation with the medical community and then with the Ministry of Health, which has led to the development of a legal basis or is in the process of being established. Onco Fertility – https://onkoplodnosc.pl We have achieved that fertility preservation will be reimbursed by the National Health Service from 01.06.2024. Divine Mothers – https://www.raknroll.pl/co-robimy/programy/boskie-matki/ They are currently working together with Professor Wielgos on the revision of these standards and possible adjustments. The issue of smoking cessation programmes was about various clinical trials conducted by companies where there were financial rewards, but at the moment, such trials are not being conducted. For more information: https://www.udzialwbadaniu.pl/kopia-male-kroki-do-wielkich-zmian. Based on the activities of patient organisations, a law has been drafted on the use of solariums, including a ban on the provision of solariums to persons under 18 years of age, a ban on the promotion and advertising of solarium services and the need to provide information on the harmful effects of UV

To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	Yes
	Work is underway to prepare a report on the implementation of the cooperation programme with non-governmental organisations for the year 2023. The obligation to prepare the report results from Article 5b (3) of the Act on public benefit activity and voluntary work (Journal of Laws of 2023, item 571), according to which the government administration body, no later than 30 April each year, publishes in the Public Information Bulletin a report on the implementation of the cooperation programme for the previous year. The report will contain information on all tasks/initiatives/projects/activities undertaken with non-governmental organisations in 2023, including data on: – concluded agreements to support or entrust the implementation of public tasks with non-governmental organisations based on open competitions conducted (number of agreements concluded and data of organisations); – granted honorary patronage of the Minister of Health or

	participation in honorary committees for projects implemented by non-governmental organisations (number of projects and data of the organiser); – Offers for the implementation of tasks commissioned to non-governmental organisations that met the conditions of formal evaluation (number of offers and data of organisations). As well as information on forms of cooperation with the Council of Patients' Organisations under the Minister responsible for Health (ROP), including: – participation of ROP members in Teams established by organisational units of the Ministry of Health, – participation of ROP members in pre-consultations and public consultations of draft legal acts, – participation in meetings of the Minister responsible for health matters or his representatives with patients' organisations, – participation of representatives of the Minister responsible for health matters and units subordinate to the Minister or supervised by him in events organised by patients' organisations, – participation of representatives of patients' organisations in the work of advisory or initiative teams created by the Minister in charge of health matters.
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible - please specify whether in health or cancer specifically]	No

[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	No
[Other, please specify]	Yes
	We do not have comprehensive knowledge on this subject. However, there are programmes implemented e.g. by the National Institute of Public Health from ministerial projects financed from EU funds in which the effect of citizens' involvement in the programme is monitored and its results published https://hcv.azurewebsites.net/Reports/GetReport. Another way of monitoring was to monitor visits to the Hepatocellular Carcinoma Prevention Programme website and the number of likes and shares of posts under the

<table>
<tr><td></td><td>education and information campaign posts. After the end of the educational campaign, the indicators will be evaluated, and the involvement of citizens will be assessed.</td></tr>
<tr><td colspan="2">What do you consider helpful recommendations for enhancing citizen engagement in cancer?</td></tr>
<tr><td></td><td>To sum up the discussion, it is considered most important to educate about healthy lifestyles so that they are adopted by young people and continued in later groups of young adults as part of a "lifestyle", it is also essential to educate already at primary school level, and to educate and encourage supervisors and company managers to support the preventive and health-promoting actions of their employees, e.g. a day off to participate in screening tests and to include screening tests or cancer diagnostics in periodic occupational health examinations.</td></tr>
</table>

Slovakia

Survey response	
Response ID	53
Date submitted	26.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Slovakia
[Which institution are you representing ?]	National Oncology Institute
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	by collecting written answers in editable pdf survey, we have prepared for this reason and by daily working experience
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Other
	a combination of the Ministry of Health, Patient organization, and Research Institution
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	https://www.noisk.sk/

[Healthcare Providers and Clinics]	Yes
	National Cancer Institute/National Oncology Institute (NOI), oncologists, gynaecologists, gastroenterologists, GPs, radiologists
[Community Events and Workshops]	Yes
	dominantly organized by patient´s and NGO organisations, Liga proti rakovine (Slovak League against Cancer), Nie rakovine (No to Cancer), Nadácia Výskum Rakoviny NVR (Slovak Cancer Research Foundation)
[Social media and Online Platforms]	Yes
	https://www.facebook.com/ligaprotirakovine, www.noisk.sk, www.onkoinfo.sk, tvdoktor.sk – audiovisual platform of Onkoinfo NGO www.onkokontrola.sk, https://www.facebook.com/MinisterstvoZdravotnictvaSR/?locale=sk_SK
[Printed Materials and Brochures]	Yes
	materials of NOI, ttps://www.lpr.sk/informacne-letaky/, https://www.lpr.sk/informacne-materialy/
[Local News and Media]	Yes
	not regularly
[Patient Support Organizations]	Yes
	https://www.lpr.sk/, http://www.nvr.sk, https://ozamazonky.sk/,

	https://www.nierakovine.sk/, http://www.ruzovastuzka.sk/, https://myelom.sk/
[Government Campaigns]	Yes
	www.onkokontrola.sk
[Educational Institutions and Schools]	Yes
	HPV coalition
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	Yes
	League Against Cancer provides comprehensible and accessible information on its website, and social media and distributes its own online and printed materials to the wider public and specialists, Information is accessible on the web portals (NOI webpage in the field of secondary prevention, LPR webpage – the field of quality of life, etc) there is information about the disease, risk factors, cancer prevention, with an emphasis on secondary prevention – screening programs. The aim is to increase awareness about cancer prevention.
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes

	e.g. in the area of survivorship care, hard-to-reach populations, translation of materials into minority languages
[3. The accessibility and clarity of communication vary.]	Yes
	by patient organizations
[4. Some improvements are needed.]	Yes
	there was missing a national approach, now we have started the campaign www.onkokontrola.sk, but there is a need for sustainability (financial and governance)
[5. There is significant room for improvement.]	Yes
	there is significant room for improvement when we are talking about vulnerable groups, and dedicated media channels informing the citizens on a regular basis. Moreover, significant improvement should be made to find a way to engage the people in all phases of activity; to hear their voices and their lived cancer experiences.
[Other]	missing information in minority languages
[Other comment]	e.g. the information is provided in the state language on the web, but in cities with a Hungarian minority, in the south of Slovakia, some doctors speak Hungarian

What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Most of the activities associated with citizen engagement are realized mainly through the activities of civil associations and patient organizations oriented toward a specific diagnosis; their topics are treatment options and quality of life, drug availability reimbursed by insurance companies, and information shared in the patient community through different events. Moreover, in the past 5 years, there has been the involvement of other institutions, e.g. Ministry of Health (MoH) and the National Oncology Institute (NOI). – Engagement of citizens or citizen representatives in public forums (seminars or workshops on various cancer-related topics etc.) and public events – Engagement of students in secondary schools – Engagement of citizens or citizen representatives in cancer-related focus groups – Citizen representatives engaging in decision-making processes in patient support organizations – Involvement of patient representatives in clinical trials – Engagement of citizens or citizen representatives on national fundraising collections and events – Round tables with participation of patient organizations, and financial support of NGOs working in the field of cancer prevention within the Action plans of the National Oncology Program

What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
	e.g. in the oncology clinical trials, there are regular meetings with the involvement of Patient organizations, ESMO Patients Guides
[3. Patient Advisory Boards]	Yes
	Media working group for screening at the MoH involves also Patient organizations
[4. Community Workshops and Forums]	Yes
	e.g. NOI forum, clinical trials workshop, different patient´s organizations events
[5. Online Platforms and Surveys]	Yes
	NOI web page/facebook, Patient organizations´ web pages/facebook
[6. Collaborative Research Projects]	Yes
	Survey in oncology screening through Media working group at the MoH
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	

[There are general training/educational programmes with specific reference to cancer]	Yes
	at the www.noisk.sk, Liga proti rakovine (Slovak League against cancer, LPR) provides informational campaigns, seminars, and interactive stands or events for the public to inform about prevention, or how to help cancer patients, or their relatives
[There are cancer-specific educational materials]	Yes
	Liga proti rakovine (Slovak League against cancer, LPR) provides educational materials through online and printed materials, or communication campaigns with their own websites, leaflets, information posters, and brochures in hospitals and oncology clinics, at NOI webpage ESMO Patients Guides, and other NOI materials available at the www.noisk.sk and some of them also in the printed form
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No

[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	Yes
[There are no corresponding educational materials]	Yes
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No

[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	the Office of Plenipotentiary for the Development of the Civil Society, https://www.minv.sk/?ros
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	Yes
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	Yes
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	Yes

[There is direct funding to support individual citizens – please specify] [Comment]	Liga proti rakovine (Slovak League against cancer, LPR) organizes the largest national fundraising event-Daffodil Day to be able to provide all its programs for oncological patients throughout the whole year. Also, many other small fundraising activities are organized throughout the year.
[There is funding for patient organisations – please specify]	Yes
[There is funding for patient organisations – please specify] [Comment]	within the Action Plans of the National Cancer Plan to support activities focused on cancer prevention, however not a sufficient amount of money is provided. Patient organizations ensure most of their funding by themselves via national fundraising events to provide all programs for oncological patients.
[Other – please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Existing activities concerning citizen engagement in health, or specifically in cancer within the country, are organized predominantly by NGOs and patient organizations via regular information based on the website, social media, newsletters, communication campaigns for all representatives, brochures, seminars, forums, interactive workshops, presentations for school and companies. The Ministry of Health,

<table>
<tr><td></td><td>together with the National Oncology Institute, patient organizations, and Health Insurance companies, has launched an umbrella communication for highlighting the participation in the cancer screening program – ONKOKONTROLA. Last year, the Ministry of Health set up an HPV coalition group to provide information about HPV vaccinations for citizens.</td></tr>
<tr><td colspan="2">To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?</td></tr>
<tr><td>[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]</td><td>No</td></tr>
<tr><td>[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]</td><td>No</td></tr>
<tr><td>[There is accessible information on whether public input was considered in decision making process]</td><td>Yes</td></tr>
<tr><td></td><td>legislative process – evaluation of comments should be published online</td></tr>
<tr><td>[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]</td><td>Yes</td></tr>
</table>

	Slovlex, platform for governmental documents – legislation process
[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	There is a need to set up a guide with rules / any mechanism, that could be helpful for national representatives / governmental organizations, to improve the engagement of citizens, but having in mind the conflict of interest in health – some NGOs represent the interests of third parties (industry) not citizens interest. Last year, the draft law was ready for parliament's deliberations about the creation of a Patient Ombudsman Institute, including a non-investment fund to support patient organizations. Now, there is a new government and other problems, but one of the law drafters is a member of the government coalition. Simply, there is a lack of legislative support for cancer. However, even that

	may not be enough, as evidenced by the current state of the National Oncology Register, which organizationally belongs to the Ministry of Health. In the field of oncology, at least the Government support is needed similarly, such as in the case of the government Council for Mental Health, e.g. the establishment of such the Council for Oncology would be highly appreciated.

Sweden

Survey response	
Response ID	41
Date submitted	17.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Sweden
[Which institution are you representing ?]	National board of health and welfare coordinating on behalf of certified CCCs and the six regional cancer centres
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	Written answers, collective input
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Cancer Centre
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	1177.se Folkhalsomyndigheten.se Livsmedelverket.se Stralsakerhetsmyndigheten.se

	Socialstyrelsen.se Cancercentrum.se Cancerfonden.se barncancerfonden.se kraftenshus.se
[Healthcare Providers and Clinics]	No
[Community Events and Workshops]	Yes
	Local symposia arranged by healthcare providers Meetings and lectures arranged by patient organizations and associations
[Social media and Online Platforms]	Yes
	Multiple sources
[Printed Materials and Brochures]	Yes
	Multiple sources
[Local News and Media]	Yes
	Relates to local arrangements and lectures
[Patient Support Organizations]	Yes
	Cancerfonden.se Barncancerfonden.se Around 30 other patient organizations with home pages
[Government Campaigns]	No
[Educational Institutions and Schools]	Yes
	HPV campaigns Healthy lifestyle initiatives

Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	No
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	Yes
[3. The accessibility and clarity of communication vary.]	Much work has been done during recent years to improve readability and access. Awareness of health literacy aspects taken into account when communication comes for governmental and/or regional or municipality bodies. Patient involvement in production of material is widespread. Patient information is increasingly translated into the most commonly spoken foreign languages and national minority languages. One area that lags behind is the information to clinical trials, which are lengthy and complex.
	No
[4. Some improvements are needed.]	No
[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	Patient organizations, NGOs and cancer centres provide various forms of citizen engagement and outreach activities, such as educational talks, fundraising activities and events,

	awareness campaigns. Special focus is on the WCD Feb 4 and most diagnoses have a special day or month, i.e. the breast cancer month in Oct and prostate cancer month in Nov. Further, Sweden's regions are participating in prevcan with information campaigns on early detection and screening in specific months throughout the year. Patients and relatives can also be included in working groups, management groups, etc. The Swedish Cancer Society strive to inform and support everyone affected by cancer, both those with cancer and next of kin, by spreading information about cancer, treatments, and research as well through our support line staffed by experienced specialist nurses in oncology or palliative care. We also try to target groups that may be difficult to reach, such as foreign-born women in socially disadvantaged areas. A specific example is material for courses in Swedish for immigrants (Sfi) together with a tutorial material for Sfi-teachers. The material, that was launched in 2023, deals with healthy lifestyles, cancer and how to reduce the risk of cancer, how to seek care and cancer screening. Among other things, you will learn what a summon to screening looks like and what it means.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	Yes
[3. Patient Advisory Boards]	No

[4. Community Workshops and Forums]	Yes
[5. Online Platforms and Surveys]	Yes
[6. Collaborative Research Projects]	Yes

What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	Yes
[There are cancer-specific educational materials] [Comment]	Provided by an umbrella NGO and by the regional cancer centres
[There are general training/educational programmes without specific reference to cancer]	Yes
	Several NGOs, authorities, health care regions and professional associations provide patient-directed education.
[There are educational materials without specific reference to cancer]	No

[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	Yes
	Swedish authorities collaborate on national guidelines for interaction with patients/citizens as regards for of information/dialog/co-creation and provide recommendations for financial reimbursement. Regional cancer centres and several health care regions also provide similar guidelines.
[There are no corresponding educational/training programmes]	No

[There are no corresponding educational materials]	No
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	Yes
	Routines and policy documents related to inabilities are implemented, depending on organization and task.
Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to	Yes

who can represent citizens' interests- please specify whether in health or cancer specifically]	
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	No
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	No
[There is funding for patient organisations – please specify]	Yes
	The Swedish Cancer Society provides financial support to patient organizations. The patient organizations are also supported by pharmaceutical companies and via the National Board of Health and Welfare's support to non-profit associations
[Other – please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	-

To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	Yes
	In most advisory panels, reference panels etc patient representatives are present at meetings and in protocols. In national clinical guidelines and standards of care patient representatives are included in working groups and listed as members of the groups.
[Public input/consultations/opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	No
[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No

[There are no mechanisms to ensure transparency]	No
[Other, please specify]	No
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	No
[Other, please specify]	Yes
	-
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	Physical meeting places. Available national information online Information about lifestyle habits and screening programs at school, via BVC, MVC and dental care, targeted health talks.

Türkiye

Survey response	
Response ID	44
Date submitted	18.03.2024
Please include the following information:	
[Which country are you completing this survey for?]	Türkiye
[Which institution are you representing ?]	Health Institutes of Turkey
[How did you collect and consolidate your answers (e.g., on the basis of a workshop or meeting, by collecting written answers...)?]	by collecting written answers
Which other stakeholders/institutions were included in gathering information for responding the survey?	
	Public Health Institute
Please describe via which channels information regarding opportunities/activities for citizen engagement in cancer, is communicated to citizens in your country. Please also include links and information on whether these information's are given on a regular basis in the comment section, if possible.	
[Public Health Websites and Portals]	Yes
	Information is provided to citizens as part of awareness activities. Additionally, necessary information and documents are available on our General Directorate's website (https://hsgm.saglik.gov.tr/en/cancer).

	Individuals can access information about which screening they can undergo and whereby entering their personal information through the "Which Screening is Suitable for Me" application. The English version of the Cancer Control Program can be accessed at the following link: https://hsgm.saglik.gov.tr/depo/birimler/kanser-db/Dokumanlar/Raporlar/Turkey_NCCP_18_April_2022.pdf
[Healthcare Providers and Clinics]	Yes
	Informative activities and disseminations about cancer are conducted through regular in-service training sessions and notes to all 81 provinces on special days, weeks, and months, as well as through collaborations with scientific advisory boards and expert associations in the field. Additionally, Family Physicians inform their target populations in their regions about cancer screenings by individually calling them through the Cancer Appointment system and inviting those eligible for screening to participate.
[Community Events and Workshops]	Yes
	Together with non-governmental organizations and professional associations, awareness activities at the community level related to special days, weeks, and months for cancer have been planned and carried out.

[Social media and Online Platforms]	Yes
	Information notes and slogans prepared for special days, weeks, and months related to cancer are published through our General Directorate's social media channels.
[Printed Materials and Brochures]	Yes
	Printed materials and brochures prepared within the scope of Cancer Awareness Activities are sent to primary health service institutions, especially KETEM (Cancer Early Diagnosis Screening and Training Centre). Additionally, they are available as print copies on the website for easy access and printing if required
[Local News and Media]	Yes
	Informational notes and awareness activities related to special days, weeks, and months dedicated to cancer awareness are published in local news and press outlets.
[Patient Support Organizations]	Yes
	Patient support services include translation services, support equipment provision, and exemptions from transportation costs, museum fees, and historical site entrance fees.
[Government Campaigns]	Yes

	An educational video emphasizing the significance of early cancer diagnosis is available on the Presidential Distance Learning Gate Platform. Patient care fees are disbursed to caregivers of cancer patients. Certain individuals diagnosed with cancer are eligible for tax exemptions on vehicle purchases.
[Educational Institutions and Schools]	Yes
	Educational institutions and schools organize various competitions such as painting, writing articles, composing poems, and creating short promotional films during special days, weeks, and months dedicated to cancer awareness.
Do you consider communication strategies, plans and materials regarding citizen engagement in health and/or specifically cancer to be easily understandable and accessible to the wider public*? Please comment on your selected choice below.	
[1. Highly accessible to all]	Yes
	Awareness trainings, website content, social media posts, and printed materials are available in multiple languages.
[2. Generally clear and accessible, but there might be room for improvement in certain areas.]	No
[3. The accessibility and clarity of communication vary.]	No
[4. Some improvements are needed.]	No

[5. There is significant room for improvement.]	No
What types of opportunities/initiatives/activities* for citizen engagement exist in your country that are related to cancer?	
	The necessary information and documents are available on the website of our General Directorate (https://hsgm.saglik.gov.tr/tr/kanser). The "Which Scan is Suitable for Me" application can be used to reach the information about the scans that needs to be done and the centres that offer the scan. With the Cancer Appointment System, family physicians call their target populations in their regions one by one and provide information about cancer screenings and invite those who are eligible for screening. Citizens who refuse screening are also informed by the call centre by phone. Tobacco Control Program, Chronic Disease Fighting Programs, sports competitions, Nutrition and Environment Cancer Campaigns are organized.
What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:	
[1. Citizens' Council]	No
[2. Consultation]	No
[3. Patient Advisory Boards]	No

[4. Community Workshops and Forums]	No
[5. Online Platforms and Surveys]	Yes
[6. Collaborative Research Projects]	Yes
What type of training programmes and/or training information materials on the topic of citizen engagement exist for individuals, civil society representatives, patient advocacy groups/representatives, NGOs, academia, industry, government/authorities etc...?	
[There are general training/educational programmes with specific reference to cancer]	Yes
	Health Education: There are various training programs available in the field of health, focusing on cancer diagnosis, treatment, and care for healthcare professionals. Seminars, conferences, and certificate programs are commonly organized by medical faculties, healthcare institutions, and professional associations. Public Health and Awareness Programs: Awareness-enhancing programs targeting the prevention, early diagnosis, and treatability of cancer are organized for the public. Such programs are typically organized by health ministries, local governments, civil society organizations, and healthcare institutions. Online Courses and Webinars: In recent years, various online education platforms offer courses and webinars related to cancer. These platforms provide education on topics such as the definition of cancer, risk factors, symptoms, treatment options,

	and quality of life. Universities and Research Centres: Universities and research centres in Turkey conduct research and educational activities related to cancer. These institutions typically organize academic programs, seminars, conferences, and workshops.
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No
[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
What type of training programmes and/or training information materials are available on the topic of citizen engagement for representatives of the healthcare system?	
[There are general training/educational programmes with specific reference to cancer]	No
[There are cancer-specific educational materials]	No
[There are general training/educational programmes without specific reference to cancer]	No

[There are educational materials without specific reference to cancer]	No
[There are no corresponding educational/training programmes]	No
[There are no corresponding educational materials]	No
[Other]	In all in-service trainings
[Other comment]	In all in-service trainings for cancer, training programs are organized on awareness, public information and the importance of health literacy, and relevant educational materials are used
Please describe what type of regulatory frameworks* are in place to define who can represent citizens' interests in your country in the area of health.	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	Patient rights legislation and institutions exist.
[Other, please specify]	No

Please describe what type of regulatory frameworks are in place to define how and where citizens can participate in cancer related engagement activities (committees, consultations, etc.)?	
[There is no regulation in place - it is not formally defined who can represent citizens]	No
[There are unspecific references (e.g., in policy documents) as to who can represent citizens' interests- please specify whether in health or cancer specifically]	No
[There are legally binding regulations on who can represent citizens interests - please specify whether in health or in cancer specifically]	Yes
	Activities of the COVID-19 Scientific Committee are being carried out in the field of health.
[Other, please specify]	No
Are there any funding incentives to support citizen engagement activities related to cancer?	
[There is direct funding to support individual citizens – please specify]	No
[There is funding for patient organisations – please specify]	Yes
	NGOs can apply for various projects. NGOs develop various projects to provide social benefits and can apply to various sources such as public institutions, private sector, international

	organizations, or donors to secure funding for these projects.
[Other – please specify]	No
Please indicate existing activities, processes and/or regulations and/or regulations concerning citizen engagement in health, or specifically in cancer, within your country that can be considered Good Practices. Additionally, please provide an explanation for why you consider these practices to be beneficial.	
	Cancer Appointment System: With the Cancer Appointment system, Family Physicians call their target populations in their regions one by one and provide information about cancer screenings and invite those who are eligible for screening. Citizens who refuse screening are also informed by the call centre by phone. It is aimed to make all our citizens aware of free screening services and to increase participation in screening.
To your knowledge, are there any mechanisms or measures to ensure transparency on the extent to which the input of citizen representatives has been considered within decision-making processes (e.g., publicly available opinion on a law* statements, input by citizen representatives or any other form of public feedback or input)?	
[Contributions by citizen (and patient) representatives, in the form of input or feedback, are protocolled and made transparent within documents (please specify format)]	No
[Public input/consultations/ opinion on a law regarding proposed laws is made publicly visible – please specify whether in health or cancer specifically]	No

[There is accessible information on whether public input was considered in decision making process]	No
[There are platforms for public feedback, such as websites that allow for public online feedback, please specify format and whether in health or cancer specifically]	No
[There are no mechanisms to ensure transparency]	Yes
	In primary regulations, opinions can be sought from NGOs and associations in law-making processes. However, in secondary regulations, opinions are not sought from TÜSEB or in secondary law-making processes.
Is there any monitoring (or form of reflection/evaluation) on the impact of citizen engagement in cancer?	
[Yes, please specify]	No
[No]	Yes
[Other, please specify]	No
What do you consider helpful recommendations for enhancing citizen engagement in cancer?	
	Participation in screening programs should be encouraged. For instance, social media, TV, and awareness events should be organized.

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