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# Health and cancer literacy as a referral point in policy recommendations for Romania

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## Abstract

**Background** Cancer is the second leading cause of death in Romania, with gaps and inequities present across oncological care. Health and cancer literacy are widely acknowledged as drivers of equitable care, but they remain understudied in national policies. This study aims to assess the focus on health and cancer literacy in Romania and to co-develop policy recommendations to enhance their role in cancer care.

**Methods** Desk research informed the agenda for two participatory workshops using a policy dialogue structure in Cluj-Napoca and Bucharest, Romania. A diverse group of Romanian key stakeholders engaged in identifying gaps, needs and role of health and cancer literacy, which informed the development of policy recommendations. These were later co-created with international and national experts.

**Results** The process revealed inequities in service access, workforce distribution, communication, and institutional focus on health and cancer literacy. Seven final policy recommendations were developed: three directly addressing health and cancer literacy, focused on organizational health literacy, individual-targeted campaigns, and population-level health and cancer literacy assessment; four indirectly supporting health and cancer literacy through informal caregiver support, regulation of complementary therapies, legal protection against workplace discrimination, and reintegration pathways for cancer survivors.

**Conclusion** This research is especially important to Romania since it co-developed policy recommendations on health and cancer literacy, an area that has received little attention in the fight for cancer equity. These recommendations can be used to open the discussion for similar gaps in other countries towards building literacy-related efforts in cancer care.

## 1 Literature review

According to the World Health Organization (WHO), cancer remains a global health challenge, with its prevalence and impact transcending borders, contributing to nearly 10 million deaths (or one in six deaths) in 2020 [1]. Collaborative efforts in research, prevention, and treatment are essential to address this complex issue and reduce the global burden of cancer [2]. In Romania, cancer ranks as the second most prevalent cause of

mortality, following cardiovascular diseases, accounting for 19% of all recorded deaths [3]. The Organisation for Economic Co-operation and Development (OECD) shows, through Romania's Country Cancer Profile 2025, that cancer mortality was higher at national level than the European Union's average for men, and lower in the case of women [4]. A snapshot of the burden of cancer in 2022 provided by the Global Cancer Observatory shows that the top three leading cancers (ranked by deaths) in Romania are lung, colorectal, and breast cancers. In 2022, Romania registered an estimated number of 104,661 new cancer cases, 56,216 cancer deaths, and 301,870 prevalent cases (5-year). The incidence rate of the top three leading cancers (ranked by cases) for males was prostate (18.2%), lung (14.8%), and colorectal (14.1%), while for females, breast (26.8%), colorectal (11.6%), and cervical cancer (7.1%) [5].

These outcomes suggest improvement is needed in terms of timeliness and effectiveness of treatment, as cancer screening rates are much lower compared to the EU average [6]. Disparities due to socioeconomic status, education, residency, ethnicity, access to health, and health literacy levels of individuals are factors among others that need to be considered to improve outcomes [6, 7].

### 1.1 Defining health and cancer literacy and unveiling their significance

Health literacy (HL) is a concept that has gained attention at the international level. Originating in the 1970s to gauge patients' grasp of medical information, HL has evolved into a multifaceted concept. Nowadays, there is a comprehensive, consensus-based definition of HL, asserting that "health literacy is closely linked to literacy and entails people's knowledge, motivation, and competencies to access, understand, appraise, and apply information to form judgments and to make decisions in everyday life concerning healthcare, disease prevention, and health promotion, to maintain and improve the quality of life during the life course". It now encompasses multiple skills, such as interpreting written health information, effectively communicating needs to healthcare professionals, and understanding health instructions which expands its significance to public health [7].

Recently, HL has been recognized as a critical predictor of the cancer care continuum [8]. HL is frequently associated with inequality in health, either as a social determinant of health or simply as a link between socioeconomic factors and particular medical outcomes, habits related to health, as well as accessibility to health resources [9]. Reduced HL is more common in individuals at higher risk for both diminished social and physical health, such as vulnerable populations. The long-term treatment plans, complex therapeutic regimens, and emotional challenges associated with cancer care underscore the importance of HL. Lower HL is linked to a diminished understanding of cancer control, heightened misconceptions about cancer susceptibility, the advantages of early detection, and the prognosis associated with it [10]. Ultimately, the impact of cancer-related cases and death is connected with socioeconomic determinants that need a recognition of HL throughout daily activity [11]. Additionally, it may impact the source and accuracy of information received, ultimately influencing participation in cancer screening [10]. Cancer literacy (CL) is deeply intertwined with the broader concept of HL, as a solid foundation in HL is crucial for patients with chronic conditions like cancer. While CL is a specific aspect of HL, the two are inherently linked [12].

CL has been defined as "all the knowledge a layperson needs to possess to understand the information and advice the health system has to offer with regard to preventing, diagnosing and treating cancer" [8]. Research has demonstrated that a patient's understanding of their disease, the intricacies of treatment plans, prognosis, and the management of potential complications significantly influences positive outcomes in cancer treatment and recovery [13]. This highlights the vital role that both CL and HL play in empowering patients to effectively navigate their healthcare journey [13].

Despite the effectiveness of evidence-based cancer prevention initiatives and the improved overall survival rates among the general population, individuals with limited CL seem to experience a reduced ability to proactively handle their risks. Even individuals with an adequate level of HL may find it challenging to comprehend intricate and advanced cancer treatments. CL is critical to "navigating the healthcare system" to identify the appropriate healthcare provider, pursue follow-up discussions on test outcomes, and ensure prompt access to treatment or participation in clinical trials [8].

### 1.2 Cancer policy consistency and how this can be linked to cancer survival

Achieving optimal outcomes in cancer care demands a comprehensive and systematic approach that spans the entire cancer continuum, from primary prevention through early detection, diagnosis, and treatment, to palliation and end-of-life care and the phase of living with and beyond cancer. Ideally, such an approach should be seamlessly integrated into a national cancer control program. Despite the widespread adoption of cancer plans across many countries, their effectiveness varies significantly in scope and depth.

Establishing direct connections between these plans and broader population health outcomes presents challenges, given the complex relationships among patients, healthcare organizations, and health systems. While a cancer plan undoubtedly plays a vital role in enhancing cancer outcomes, its stand-alone efficacy is questionable. Any potential benefits it offers may be influenced by the broader policy and systemic context, emphasizing the need for a context-aware approach to cancer care [14]. In this regard, structural factors such as policies, legislation, regulations, government programs, and actions in the field of cancer are crucial for reducing inequalities in cancer prevention, detection, treatment, and survival [6, 7].

Therefore, this study aimed to map out and co-construct national-level policy recommendations that place health and cancer literacy at the core of efforts to reduce cancer care inequities. These recommendations, which address a variety of barriers in the oncological field, are intended to serve as an entry point for equitable cancer prevention, diagnosis, and treatment and are relevant for all professionals working in the cancer domain. The study underscored the momentum for action with a start from analyzing diverse institutional streams, such as national strategies, legislation, policy documents, and emerging interest in improving population-level literacy. The work undertaken is distinct in its cross-sectoral approach in Romania and its explicit focus on aligning literacy initiatives across cancer policy.

## 2 Methodology

The methodology of the study consisted in a policy dialogue to formulate a set of policy recommendations. The policy dialogue was structured using the WHO EVIPNet Europe Policy Dialogue Preparation and Facilitation Checklist [12] and the SUPPORT Tools (STP 14) [10]. The main data sources for the documentation of the policy recommendations were: (1) information generated by a two-step desk research: where during the first step, Romanian cancer policies, regulations, programs and action plans to identify opportunities for incorporating health and cancer literacy were primarily reviewed, followed by the second step where a narrative review was deployed to explore international findings related to health and cancer literacy, (2) stakeholder viewpoints expressed during two workshops: one local in Cluj-Napoca and one national in Bucharest, (3) notes from the project team's observations as participants, facilitators and organizers of the policy dialogue process.

The study was initiated by the first step of desk research, focusing on national landscape of cancer care, health literacy and cancer literacy. Based on these findings an agenda with discussion key points was prepared for the local level meeting with stakeholders. The key points served as means of engagement during the meeting, allowing stakeholders to explore practical challenges and identify what they regarded to be the key areas for intervention (Annex 2). These priorities were explored through another phase of desk research. The second step of desk research was deployed in the format of a narrative review mainly to identify international solutions that could be adapted to suit the national landscape (Annex 1). As a result, a draft of policy recommendations was elaborated and explored in detail during the second meeting with stakeholders, which led to revision and refinement of recommendations. The new improved version of policies (an outcome of the second meeting) went through an iterative co-drafting with the aid of targeted online reviews, starting from national stakeholders and continuing with the input of selected international experts with experience in cancer care and policy. All suggestions were systematically incorporated, and the final policies recommended (available in Table 1 and Annex 3) were recirculated to confirm that no further changes were required.

1. The first step of desk research was conducted between December 2022 and April 2023 (up until the first meeting organized) and aimed to identify the existing policies, legislations, regulations, government programs, and action plans focusing on cancer care, health and cancer literacy.

The search for publications was done on Google Scholar utilizing text word strategies. The primary terms were 'cancer', 'health literacy', 'cancer literacy', 'action', 'patients', and 'caregivers'. The results were confined to Romanian and English-language scientific articles published between 2015 and 2023 that focused explicitly on HL and CL in Romania. The starting point of 2015 was chosen to capture the period during which HL began to gain recognition as a key element in international health policy agendas, leading to its integration into national strategies and cancer-related policy discussions that have shaped both regional and national approaches to CL [14].

Afterward, an iteration to find and examine the most recent national documents in Romanian was deployed to summarize the current and most recent scenario that patients, caregivers, and professionals are experiencing in the fight against oncological

**Table 1** The final set of policy recommendations to achieve equity in cancer care, by focusing on action points for health and cancer literacy

| Identified problem | Impact on health literacy and cancer literacy | Recommendations | Proposed action points | Time frame of action points | Institutions liable for implementation | Beneficiaries | Process behind the solution |
|---|---|---|---|---|---|---|---|
| 1. Lack of information about the level of cancer literacy among oncological patients and informal caregivers | Direct | National-level assessment of cancer literacy among patients with oncological pathologies and their informal caregivers | Assess health literacy levels among cancer patients and informal caregivers using specifically designed instruments (e.g., Cancer Health Literacy Test-30 (CHLT-30)) and models (e.g., Yuen et al.)<br>Improve data collection, by engaging patients and informal caregivers in research studies | Short-term (up to 1 year)<br>Medium-term (up to 5 years) | Ministry of Health, National Institute of Public Health, Directorate of Public Health, with the support of NGOs | Oncological patients, informal caregivers of patients with oncological pathologies | Plan to measure health literacy levels of patients and informal caregivers<br>Identify cancer-literacy-specific tools to assess the level of literacy<br>Identify institutions to support implementation and train professionals for data collection<br>Recruit and involve national, regional and local NGOs of oncological patients to document real-life experiences of patients and informal caregivers through case studies to provide deeper insight into how low health literacy affects cancer care, further helping tailor education and awareness programs |
| 2. Insufficient knowledge among the population regarding health prevention initiatives, including those related to cancer prevention | Direct | Improving health and cancer literacy among individuals | Introduce age-appropriate health education courses from kindergarten to university, tailored to different cognitive development levels<br>Implement public health campaigns and community outreach initiatives to raise awareness about cancer at all levels of prevention. | Long-term (up to 10 years and beyond)<br>Long-term (up to 10 years and beyond) | Ministry of Education and Research, Ministry of Health, National Institute of Health, The Directorate of Public Health, School Inspectorates, with the support of NGOs | National population | Develop and integrate health education curricula that addresses cancer risk factors and early detection<br>Ensure collaboration between ministries to reach the target population and provide the necessary tools<br>Target and train professionals working with vulnerable populations<br>Develop effective health campaigns and community outreach to ensure widespread dissemination, particularly targeting underserved and marginalized communities |

**Table 1** (continued)

| Identified problem | Impact on health literacy and cancer literacy | Recommendations | Proposed action points | Time frame of action points | Institutions liable for implementation | Beneficiaries | Process behind the solution |
|---|---|---|---|---|---|---|---|
| 3. Unmet needs of informal caregivers and burden associated with their responsibilities | Indirect | Emphasizing the role of informal caregivers in providing support to cancer patients | Organize awareness-raising sessions to recognize the role of informal caregivers among healthcare professionals<br>Develop training programs for healthcare staff to improve communication with informal caregivers and patients<br>Distribute personalized guides to informal caregivers with practical information and support resources | Medium-term (up to 5 years)<br>Long-term (up to 10 years and beyond)<br>Medium-term (up to 5 years) | Ministry of Health, National Institute of Health, Hospitals | Informal caregivers of cancer patients, Oncological patients | Develop training sessions among healthcare professionals tackling topics related to the impact and needs of informal caregivers<br>Create training programs to facilitate effective communication within the healthcare triad of professionals, patients, and informal caregivers<br>Design and widely disseminate guides with clear, positive language based on the ACP Communication Model for Health Literacy. |
| 4. Lack of focus on organizational literacy | Direct | Improving organizational health and cancer literacy | Develop and implement health literacy programs in hospitals, supported by financial incentives<br>Ensure adequate hospital signage and develop a concise referral system to guide patients and informal caregivers | Medium-term (up to 5 years)<br>Long-term (up to 10 years and beyond) | Ministry of Health, Hospitals | Patients, Informal caregivers, Healthcare workforce | Create health literacy programs and set performance-based financial incentives<br>Ensure the availability of all support services necessary, including patient navigation (involving patient navigators)<br>Aid in the implementation of clear signage and a referral system to facilitate navigation within healthcare facilities |

**Table 1** (continued)

| Identified problem | Impact on health literacy and cancer literacy | Recommendations | Proposed action points | Time frame of action points | Institutions liable for implementation | Beneficiaries | Process behind the solution |
|---|---|---|---|---|---|---|---|
| 5. Inappropriate use of complementary and alternative medicine (CAM) therapies among oncological patients | Indirect | Identifying the role and use-level of complementary and alternative medicine (CAM) therapies in oncology | Conduct research studies to identify the prevalence and types of CAM therapies used by cancer patients<br>Foster open discussions between healthcare professionals, patients and informal caregivers about CAM therapies from diagnosis and throughout the treatment process<br>Ensure the collaboration of healthcare professionals with trusted CAM practitioners to ensure patients receive safe and regulated CAM therapies | Medium-term (up to 5 years)<br>Medium-term (up to 5 years)<br>Long-term (up to 10 years and beyond) | Ministry of Health, Public and private healthcare institutions | Oncological patients, Informal caregivers of patients with oncological pathology, Healthcare professionals | Prepare and conduct national-level research on CAM therapies usage among oncology patients and the involvement of informal caregivers and community in the uptake of such therapies<br>Train healthcare professionals on CAM therapies used for oncological afflictions and patients' perceptions about these therapies<br>Encourage and establish training sessions for continuous dialogue between healthcare providers, and between patients and providers about CAM therapies<br>Identify and establish contact with reputable CAM practitioners to provide coordinated care |
| 6. Workplace discrimination against both cancer patients and their informal caregivers | Indirect | Enforcing access to free socio-legal counseling | Enforce legislation pertaining to free socio-legal counseling for cancer patients and informal caregivers<br>Develop a national monitoring system to track inequalities in oncological care, similar to the ECIR's Cancer Inequalities Registry. | Medium-term (up to 5 years)<br>Long-term (up to 10 years and beyond) | Ministry of Labour and Social Solidarity, Territorial Labour Inspectorates, Ministry of Health, Hospitals, NGOs, Health Navigators | Oncological patients, Informal caregivers | Provide counseling sessions on rights and support for cancer patients and informal caregivers, ensuring they are informed about current legislation and available resources<br>Prepare, train and involve national and international specialists in developing a national monitoring system for cancer-care inequalities |

**Table 1** (continued)

| Identified problem | Impact on health literacy and cancer literacy | Recommendations | Proposed action points | Time frame of action points | Institutions liable for implementation | Beneficiaries | Process behind the solution |
|---|---|---|---|---|---|---|---|
| 7. Challenges faced by pediatric and adult oncological survivors of cancer in reentering society | Indirect | Reintegration in the workplace for cancer survivors and in school for pediatric cancer survivors | Provide tax incentives for employers who hire or retain cancer survivors<br>Develop specialized reintegration programs for adult cancer survivors to support their return to the workplace and prevent discrimination<br>Develop specialized reintegration programs for pediatric cancer survivors to support their return to school and prevent discrimination | Medium-term t (up to 5 years)<br>Long-term (up to 10 years and beyond)<br>Long-term (up to 10 years and beyond) | The Ministry of Labour and Social Solidarity, Ministry of Health, Ministry of Education and Research, Public and Private Employers | Oncological survivors, both adults and pediatrics, Informal caregivers | Implement legislative changes to offer tax incentives for employing cancer survivors<br>Develop a pathway for social rehabilitation of oncological survivors<br>Create comprehensive reintegration plans for pediatric survivors, involving collaboration between parents, teachers, and school staff to support educational participation |

diseases. For this reason, an initial Google search was undertaken to gain awareness of the existing national position in cancer care, the challenges, and facilitators to adopting the best quality of care. To complement the findings from the initial Google search, more focus was placed on conducting an in-depth exploration of the Romanian oncological institutes' official websites, along with key legal documents and frameworks, and current/future national plans and strategies for health and care. Some of the following documents were included: the two initial National Plans to Combat Cancer, the two National Health Strategies, respective for 2022–2030 and 2023–2030, and laws concerning patients' rights and caregiver support (Law No. 46/2003 and Law No. 24/2022). The goal was to ensure that the recommendations resulting from this study were not redundant and can be further sustained and executed when national strategies and plans are advanced.

The best evidence at hand from the literature and multiple institutional websites was gathered, examined, and summarized into key points of discussion. The insights gained from these sources led to a deeper understanding of the current state of cancer care and the inequities that patients and caregivers face in Romania, as well as specifics that CL presents at the national level. The synthesis and analysis of information from these sources laid the groundwork for a selection of key topics that were discussed during the project's second phase: organizing the local level workshop, with the goal of strengthening the credibility of the theoretical findings from desk research and simultaneously gathering additional knowledge based on the practical perspectives of professionals working in the Romanian healthcare system.

The second step of desk research was deployed starting with May 2023 (after the first meeting) until the final policy recommendations were agreed upon by all reviewers. It was deployed as a narrative review of international literature surrounding cancer care, health and cancer literacy. It was conducted in this format to support the one-year implementation timeline and objectives of the project. Sources that were not pertinent to the study's aim and had no immediate connection with policy development surrounding health and cancer literacy and the priority areas of action mentioned by stakeholders were excluded. The inclusion criteria addressed health or cancer literacy, cancer care actions connected to literacy, or relevant policy suggestions, with a focus mostly on peer-reviewed articles and few grey literature pieces from reputable national and international organizations. Search words were closely connected with the main priority areas found during the first meeting, such as 'CAM therapies in cancer care', 'CAM therapies interventions', 'CAM therapies and health literacy', 'role of informal caregivers', 'needs and challenges of informal caregivers', 'health and cancer literacy of informal caregivers', 'workplace discrimination of cancer patients', 'workplace discrimination of informal caregivers of oncological patients', etc. Each area had a dedicated time of search for relevant information, and the main sources that were selected to inform the policies are reflected in Annex 3. Rather than a thorough review of the literature, the sources were chosen based on how applicable they were to the national context and relevance. In order to inform stakeholder dialogue and the co-creation of national-level implementable recommendations, it was necessary to balance the study methodology and feasibility within the project duration. This was reflected in the selected time frame, giving priority to evidence highly related to health and cancer literacy.

2. One workshop at the local level was organized in Cluj-Napoca in May 2023 to discuss and refine the findings from the first step of the desk research. Another workshop at the national level was organized in Bucharest in November 2023 to open a policy dialogue and further generate momentum in co-creating policy recommendations together with key stakeholders from the cancer field in Romania and internationally.

3. Workshop at local level, May 2023, Cluj-Napoca, Romania.
   The event's rationale was to gather professionals with "know-how" in the health and cancer field and eventually foster collaboration and start a policy dialogue. A stakeholder database was created in advance, comprising potential participants with expertise and professional involvement in the fields of cancer care, public health, and health and cancer literacy. Stakeholders were identified either through direct, named professional contacts or via relevant public institutions, professional associations, non-governmental organizations, universities, and health-care-related organizations, which were invited to nominate appropriate representatives. Twenty entities were contacted through multiple communication channels, including email invitations, telephone calls, and direct face-to-face invitations. Following two to three rounds of follow-up communication, participation was confirmed by 14 stakeholders, who attended the event.
   The fourteen attendees encompassed key informants and authoritative figures in the health and cancer fields, including an oncology patient navigator, a representative from the group in the Romanian Parliament dedicated to the Fight Against Cancer initiatives, a senior advisor from the National Agency for Health Programs (Ministry of Health), an oncology patient representative from a non-governmental organization (NGO), four public health specialists (academics) on health literacy and health care, a delegate from the Centre for Innovation in Medicine, a delegate from the Regional Health Insurance House, a medical genetics specialist, and three professionals from the Cluj-Napoca Oncology Institute, including a medical director, a medical doctor, and a resident doctor. During the working meeting, the findings from the first step of desk research were discussed, and further key aspects were explored and refined, such as the role of health professionals in reducing existing disparities in cancer care, the role of individual patient characteristics such as (socioeconomic status, education, residency and ethnicity, access to health, and health and cancer literacy, etc.) in improving/hindering equity in cancer care.

4. Workshop at the national level, November 2023, Bucharest, Romania.
   Based on both findings from the second step of the desk research and the workshop at the local level, the next phase consisted of drafting a preliminary set of policy recommendations to improve equity in cancer care. These recommendations focused on the health system and social determinants of health, such as individual characteristics and health and cancer knowledge, structured in a manner to inform direct and indirect impact on health and cancer literacy. The draft of policy recommendations served as a starting point in the co-creation activity during the workshop at the national level. Similarly, for the national-level workshop, a stakeholder database was developed, targeting individuals and institutions active in the fields of cancer policy, cancer care, public health, and health and cancer literacy. Invitations were extended either

directly to identified experts or through public institutions, academic institutions, non-governmental organizations, and patient advocacy organizations, requesting the nomination of suitable representatives. Thirty entities were contacted using similar communication channels as at the local level. Despite repeated follow-up efforts, participation at the national level proved more challenging, partly due to geographical distance and competing professional commitments. Ultimately, seven stakeholders confirmed and attended the event. Nevertheless, the composition of participants ensured the inclusion of diverse perspectives, encompassing patient advocacy, public health institutions, health journalism, and expertise related to the development and implementation of the national cancer plan.

The seven attendees encompassed key stakeholders and authoritative figures in the health and cancer fields, including board member of Cancer-Plan.ro, a representative of the National Institute of Public Health (INSP), a health journalist, a board member from a patient advocacy NGO, and three public health specialists (with expertise on health literacy and health policy) from Babes-Bolyai University, Cluj-Napoca, Romania. The attendees received the draft document prior to the event day.

5. The study team contributed and participated throughout all the phases of the study: design, management, documentation and facilitation of the policy dialogue, draft development and finalization of the policy recommendations. Although the team had multiple roles in the study, including organizing the meetings, analyzing the discussion findings, and drafting the first set of policy recommendations, to reduce the risk of predisposition, several steps were undertaken: (1) a project consultant facilitated both in-person dialogues; (2) roles within the team were clearly defined; (3) volunteers and independent venues were consulted so that the team was not involved in managing arrangements throughout the events; (4) recommendations were strengthened through external review with national and international experts; (5) expert feedback revised the recommendations iteratively. These steps allowed the team to focus on one specific goal for each event at a time, listening to the dialogues and taking detailed notes, as not being involved altogether in steering the discussion.

All preparatory documents, meeting minutes, workshop notes were collected and analyzed to create a high-level summary and design the policy recommendations. Two members of the research team independently reviewed all documentation to identify recurring topics, key issues, opinions, insights, and stakeholder priorities. Both reviewers coded the documentation according to the WHO EVIPNet Europe Policy Dialogue Checklist [12] and SUPPORT Tools (STP 14) framework [10]. The unit of analysis was key points and policy-relevant statements organized into the following categories: (1) problem definition and priority articulation; (2) policy options and alternatives discussed; (3) implementation considerations and feasibility barriers; (4) stakeholder contributions and representation; (5) evidence synthesis integration; (6) consensus and disagreement points; and (7) proposed action steps and responsibilities. After independent coding using these categories, the two reviewers met to compare and discuss their results. Where coding differed, discrepancies were resolved through discussion and consensus, with particular attention to the context and intent of each passage, and when that was not possible, a third reviewer was consulted. Once consensus was reached,

potential key areas were consolidated into a shared analytical framework. This dual-review approach, grounded in established evidence-informed policymaking standards, enhanced the credibility and trustworthiness of interpretations.

## 3 Results

### 3.1 Main desk research findings

A total of 2 legislations, 4 national strategies/plans, 23 documents, 8 articles from 3 databases, and 8 websites were analyzed to draw final conclusions on the state of cancer care and cancer literacy in Romania, which can be found in Annex 1.

#### *3.1.1 Documenting actions related to health and cancer care in Romania*

Romania's National Health Strategy for 2014–2020 addressed key areas such as public health, healthcare improvement (particularly for women and children, reducing non-communicable disease morbidity and mortality, and ensuring equitable access to quality health services for vulnerable groups), health research, e-health technologies, and health infrastructure at various levels. The National Health Strategy 2023–2030, titled "Together for Health" and spanning from 2022 to 2030, builds upon its predecessor's objectives and responds to structural reforms in the health sector. It functions as the national policy framework for health [15] and is assessed against the European Commission's enabling condition for health, encompassing the development of the Partnership Agreement and programs from 2021 to 2027. The strategy addresses country recommendations issued by the European Commission regarding the healthcare system. The National Health Strategy 2023–2030 focuses on three strategic interventions: safeguarding and promoting public health, delivering high-quality and accessible healthcare services and technologies, and ensuring the efficiency and coherence of the entire healthcare system. The strategy identifies several structural gaps and addresses future action on topics such as equity and population-level education for prevention. However, health literacy was not explicitly mentioned throughout the document [15]. Even though these concepts are so closely intertwined, they are two different fundamental principles of patient involvement and chronic care.

Another document that was subjected to analysis was the Romanian National Cancer Plan, launched in January 2022, following collaboration between the Chamber of Deputies of the Parliament and the Ministry of Health to align with the European cancer guidelines [16]. In November, during the same year, the plan was adopted under Law No. 293/2022 of 3 November 2022, for preventing and combating cancer, with the stated aim of delineating the patient journey to ensure a comprehensive, multidisciplinary approach. Through one of its objectives, the plan outlines the commitment to improve and embed community-based health literacy into national cancer care planning. It promotes inclusive education and communication frameworks designed to reach vulnerable groups and address disparities in cancer outcomes. The National Cancer Plan includes regionally guided prevention strategies and patient education efforts [17]. Additionally, specific objectives of the plan encompass the creation of a health innovation fund for early access to cutting-edge therapies; the provision of additional services for cancer patients, including nutritional guidance, psychological support, and palliative care; the formulation of a prevention strategy with the monitoring of risk factors; the establishment of a National Cancer Registry linked to the European Network of Cancer

Registries; regular updates of clinical guidelines and treatment protocols; and the introduction of a tumor board in cancer care for reviewing patient conditions and discussing personalized treatment options [18].

Romania does not yet (at the moment of writing this article) have an operational National Cancer Registry, though one is being developed with EU support. Thus, reporting cancer incidence in the standard information system varies across regions. The legislation regarding the population-based registration of cancer cases to establish the National Cancer Registry is represented by the Order of the Minister of Health 2027/2007; however, implementation has been limited, and adherence of providers of diagnostic and cancer treatment medical services to the provisions of the order has been variable [19].

Early detection and cancer screening are recognized as priorities in public health interventions within the previous health strategy for 2014–2020; however, systematic cancer screening practices vary in Romania, and expenditures on preventive measures differ across regions [16]. Access to care for cancer patients varies geographically and by payment capacity. Differences between various levels of services and variations in the distribution of technology and specialists result in patients resorting to privately paid services for a quicker diagnosis. Direct payments accounted for 18.9% of current health expenditures in 2019, compared with the EU average of 15.4% [16].

Patient oncology care is provided in public and private healthcare facilities, with an estimated 3500 beds nationwide (2020). The volume of oncological care services varies across regions and is concentrated in major university centers. Oncology departments in county hospitals operate with varying roles, with some serving as intermediate stations with patients being transferred to oncology institutes or university centers. The distribution of cancer care services varies between regions and within counties. Between 2005 and 2015, the number of oncologists per 100,000 inhabitants increased; however, the absolute numbers and distribution across regions remain variable [16].

### 3.2 Findings from the workshops

#### *3.2.1 Workshop at local level*

The first step of desk research findings guided the development of four key discussion points for the workshop at the local level:

6. Cancer patients' perspective and experience in the Romanian healthcare system: Addressing issues faced by patients or their family/caregivers, such as late diagnosis, lack of information, and difficulties in obtaining treatment. Exploring potential solutions and policy options.

   Points covered: Barriers encountered by cancer patients and their caregivers regarding access to medical services and interaction with healthcare personnel, current management strategies for these barriers, and proposals for actions to improve their journey within the medical system.

7. Cancer inequalities in Romania and their manifestation across patient populations: Discussing variations in access to medical services and treatment in urban vs. rural areas, including aspects related to treatment access, costs, and community care. Exploring potential solutions and policy options.

Points covered: Barriers encountered by medical staff in managing oncology cases encountered at the interface with the medical system, in communication with patients and informal caregivers, or related to the health literacy level of patients (prevention, diagnosis, treatment, survival). Current management approaches and recommendations for improvement.

8. Existing national policies for cancer prevention and treatment in Romania and recent developments: Discussing how policies might be adapted to support more equitable access to medical services and treatment for all cancer patients, as well as to strengthen the level of health and cancer literacy among patients and their families. Exploring potential solutions and policy options.

   Points covered: Opportunities for addressing health and cancer literacy in oncology through early inclusion of specialized palliative care personnel and patient navigators in the healthcare process.

9. Examples of non-governmental programs and initiatives in reducing cancer inequalities in Romania: Discussing how governmental policies and actions might support such initiatives. Exploring potential solutions and policy options.

   Points covered: Facilitators and barriers encountered in collaboration and governmental support of NGOs working with cancer patients and their families. Proposals for actions to address encountered barriers.

The engagement and practical examples of professionals provided details that had not been identified during desk research, which can be found in Annex 2. Nine potential areas for further exploration emerged during this initial workshop and are presented in Fig. 1. Although these new areas were first raised during specific discussion points of the meeting agenda, they were observed to be interconnected, with many having implications across all four discussion points.

#### *3.2.2 3.2.2 Workshop at national level*

The national workshop refined and expanded the identified areas for action (Fig. 1) into two overarching categories: (1) direct impact on HL, and (2) indirect impact on HL (addressing access to medical services for oncological patients).

10. Category (1) of policies aimed at developing programs to strengthen HL at the level of hospitals, NGOs, and support associations. This includes the assessment and development of individual literacy at the population level and among healthcare personnel and healthcare institutions.
11. Category (2) of policies addressed four key aspects of cancer management in Romania. This includes:

    - creation of a regional pathway for oncology patients.
    - identification and integration of complementary and alternative therapies within evidence-based frameworks.
    - recognition of the role of informal caregivers in supporting oncology patients.
    - legal protection for both oncology patients and informal caregivers against workplace discrimination.

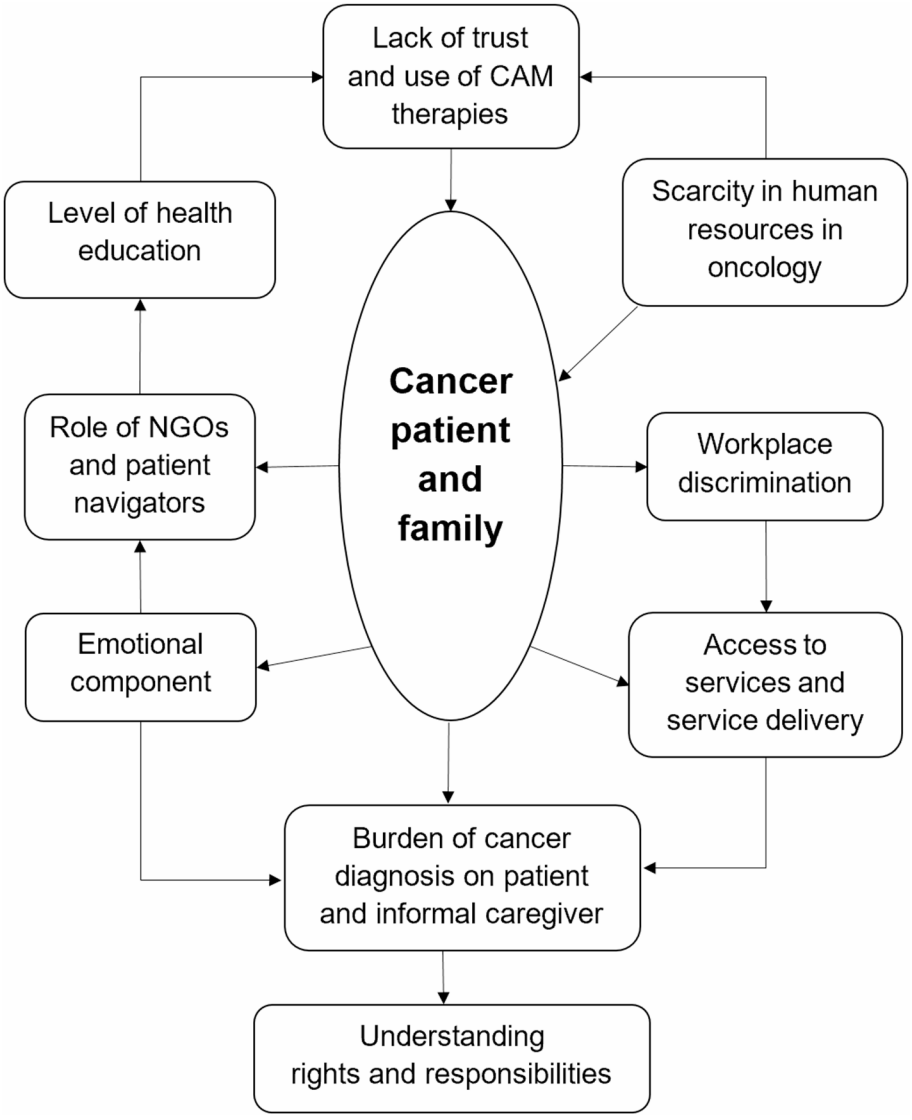


**Fig. 1** Intervention areas supporting cancer patients and families

This set of policy recommendations was refined based on suggestions and discussions with attendees from the local and national workshops and was finalized after the iterative co-drafting with the aid of targeted online reviews, starting from national stakeholders and continuing with the input of selected international experts with experience in cancer care and policy. Table 1 provides the final set of policy recommendations to advance equity in cancer care, including action points for health and cancer literacy.

## 4 Discussions

### 4.1 Translation of findings into policy imperatives

This study aimed to develop evidence-informed, national-level policy recommendations that place health and cancer literacy at the core of efforts to reduce cancer care inequities in Romania. Through a structured, iterative methodology combining desk research, local and national stakeholder engagement, and expert co-drafting, nine action areas emerged, which were subsequently consolidated into seven policy problem areas with

corresponding recommendations. These areas were not randomly identified but rather surfaced consistently across diverse stakeholder groups and align with documented barriers in the European and international cancer policy landscape.

The identified gap in cancer literacy assessment (Table 1, Problem 1) reflects a broader European challenge: most countries, including Romania, lack systematic, population-level measurement of health and cancer literacy among oncology patients and their caregivers. Without such data, healthcare systems cannot effectively target interventions or monitor progress toward equity. The proposed policies also tackle addressing the social determinants of health, recognizing that factors such as education, socioeconomic status, and geographical location play a significant role in access to care. By promoting equitable access to information and resources, the policies seek to reduce the barriers faced by disadvantaged communities, ensuring that cancer prevention and treatment services reach those who need them most. The emphasis on age-appropriate health education from kindergarten onwards (Table 1, Problem 2) responds to evidence that early health literacy intervention produces sustained long-term benefits in health decision-making, disease prevention, and health outcomes across the lifespan. To provide practical guidance for improving health and cancer literacy, existing European materials and tools can be used. These include the BUMPER cancer prevention factsheets, which provide clear and accessible educational content [20]; the BUMPER Health Literacy Guides for professionals [21]; the iNTERVENE project's online resources and multimedia tools for patients and health practitioners [22]; the BCLEAR initiative's culturally adapted educational campaigns and decision-support materials [23]; and the CHOICE project's multilingual digital resources supporting shared decision-making for high-risk populations [24]. These resources offer concrete, evidence-informed examples that can be adapted and tailored for Romania to complement the policy recommendations developed in this study.

Additionally, putting more emphasis on the role of informal caregivers in the healthcare process is another key aspect of the recommendations. The recognition of informal caregivers' unmet needs and burden (Table 1, Problem 3) addresses an often-invisible healthcare workforce. Caregivers often play a crucial role in supporting cancer patients, yet their needs are frequently overlooked. By providing them with the necessary resources, training, and support, these policies will have the potential to reduce the burden on caregivers while improving patient care. Organizational literacy and ensuring that healthcare facilities themselves communicate in accessible, clear, and patient-centered ways (Table 1, Problem 4) emerged as a distinct need because systemic barriers (navigation difficulties, unclear signage, fragmented communication between departments) amplify and often reinforce individual health literacy gaps. Evidence demonstrates that health-literate organizations can mitigate low personal health literacy and significantly improve cancer patient outcomes [25]. Existing data shows that improved personal CL combined with health-literate organizations and systems can improve the quality of care and health outcomes among patients with cancer [13]. Health care institutions must consistently and systematically react to the needs of the patients in regards to HL. They need to make health services and information more approachable and inclusive. Although some progress has been made in the last 15 years [26], more emphasis needs to be put on ways to appropriately address the low levels of HL. While digital health literacy is increasingly important for cancer prevention, in Romania broader

foundational challenges remain, including limited access to basic health information and structural barriers in the healthcare system. Many population groups, especially older adults and those in rural areas, face difficulties in accessing or using digital resources effectively [27]. Therefore, this study focused on addressing core health literacy challenges first, while recognizing that improving digital health literacy represents an important area for future research and intervention as the system evolves.

Decreased HL among cancer-prone populations also impacts screening rates, and is tied to a delayed cancer diagnosis and a greater disease progression, poor management of symptoms, and lower adherence to conventional therapies [28]. HL also stands the several factors that influence individuals' usage of complementary and alternative (CAM) therapies [29]. The focus on CAM use among cancer patients (Table 1, Problem 5) reflects a critical but under-addressed issue in oncology care. Patients frequently use CAM therapies without informing their oncologists, creating safety risks through potential drug interactions and undermining treatment efficacy [30–32], a gap that low health literacy exacerbates, as patients may lack skills to critically evaluate CAM claims or understand interactions with conventional treatment [26]. Solutions might come in the form of guidelines in clinical practice for healthcare professionals to guide patients towards safe care [33–35].

Workplace discrimination and survivor reintegration (Table 1, Problems 6 and 7), while categorized as having indirect impact on health literacy, are essential policy priorities because social determinants, stigma, and employment discrimination directly affect whether cancer survivors can apply health knowledge in practice (e.g., adhering to follow-up surveillance), maintain engagement in the healthcare system, and recover economically and psychologically.

### 4.2 Importance of the proposed policies and their implementation

To ensure successful implementation, a multi-stakeholder approach is required. Collaboration between the Ministry of Health, educational institutions, patient navigators, healthcare providers, NGOs, and community organizations is essential. This multi-stakeholder approach might strengthen public-private partnerships, as governments can support, for example, NGOs through dedicated funding opportunities. Governments could work alongside NGOs to comply with regulations and delivering outcomes, therefore enhancing the quality of services [17]. Moreover, the role and openness for funding of governments might impact the uptake and implementation of patient navigation programs across different organizations [36, 37]. At the same time, the implementation of the proposed policies can be well considered to be aligned with the EU's Multiannual Financial Framework (MFF), which sets long-term budgetary priorities. The upcoming framework for 2028–2034 represents an opportunity to press for specific funding streams to support the recommendations [19].

While the proposed policies are evidence-informed and aligned with international standards, their successful implementation faces several practical constraints and trade-offs that warrant acknowledgment. Developing a national cancer literacy assessment system (Problem 1) requires substantial funding, technical expertise, and coordination across health institutions, resources that may be limited in a transitioning healthcare system, such as Romania [4]. Similarly, integrating age-appropriate health education into school curricula (Problem 2) requires curriculum revision, teacher training, and

inter-ministerial coordination between Education and Health, which may be slow and resource-intensive.

Developing training programs for healthcare staff to improve communication with informal caregivers and distributing personalized guides with support resources (Problem 3) assumes adequate healthcare workforce capacity and institutional commitment to caregiver engagement. Current shortages of oncology professionals and gaps in continuing education infrastructure may slow roll-out [4]. Organizational literacy improvements (Problem 4) assume that healthcare facilities can be reorganized to prioritize patient-centered communication. However, many Romanian hospitals operate under resource constraints that may limit their capacity for such systematic changes [4]. Implementation timelines may need to be extended beyond the proposed 5–10 year periods to account for institutional capacity-building.

Fostering open discussions between healthcare professionals and patients about CAM therapies and establishing collaboration with CAM practitioners (Problem 5) assumes professional willingness and regulatory frameworks that do not currently exist in Romania. Professional skepticism among oncologists and gaps in evidence for CAM safety in oncology contexts may hinder adoption. Development of credentialing standards and safety guidelines will require substantial time and coordination before implementation can proceed effectively.

Enforcing anti-discrimination legislation and providing tax incentives for employers who hire cancer survivors (Problems 6 and 7) assumes adequate labor inspection capacity and employer willingness. Many regions with high unemployment and weak institutional infrastructure may lack the capacity to implement these measures effectively. Timeline extension beyond the proposed 5–10-year period may be necessary to allow for cultural shifts and institutional capacity-building in employment services and workplace practices.

As we continue to strengthen support for adult cancer survivors, it is equally important to focus on children who are cancer survivors and ensure their successful reintegration into school. Going back to school represents a transition from an unexpected health status to everyday routines. These survivors felt that resuming their school activities gave them a sense of belonging, value, and social connections. Reintegration into school is critical for the child's regular growth and development of academic skills [38].

The recommendations address the seven interconnected problem areas simultaneously. While this comprehensive approach is theoretically sound, implementation priorities may need to be sequenced (e.g., national literacy assessment before designing interventions) to avoid overwhelming the health system in Romania. These challenges do not negate the policy recommendations but rather highlight the need for phased implementation, realistic timelines, continuous monitoring, and adaptive management as the health system evolves.

### 4.3 Contribution to equity, health literacy, and cancer literacy

Although some of the recommended policies have no direct influence on HL or, implicitly, CL, they are closely linked since many issues that develop in the healthcare system and receive funding are not directed at the upstream factors. Low levels of HL have an impact on all processes in the healthcare system, whether obvious or not, putting pressure on the healthcare workforce in particular. This happens due to the fact that HL

stands as an essential component of patient-doctor encounters [39]. Also, HL has grown into a progressively significant problem of interest in the health field due to its strong relationship to the efficiency of health services and lower health-care costs [28]. All of this can be observed and tackled throughout the implementation of the National Plan for Beating Cancer, with the aid of one essential component, a population-based cancer registry. Registry systems for diseases serve an important role in improving medical results through the supply of extensive information that informs medical care, research studies, and policy decisions. Registries capture real-world data which is critical to understanding illness prevalence, efficacy of therapies, and effects for patients [36, 37]. For example, one study used institutional data to look at the association amongst all-cause mortality and HL across cancer types. Results showed that higher levels of HL are linked with a nearly nine-month rise in overall survival [40].

At the same time, improving HL may not only benefit patients, but also their informal caregivers. Although they play critical roles in the pathway of cancer patients, these caregivers sometimes take on the job without much awareness about the complexity of their role or extensive previous training. Thus, a focus on HL and CL of informal caregivers might be helpful for them to learn how to navigate the commitments that come with caregiving [41]. Whether targeting patients or informal caregivers, it is vital to study and comprehend the function and effects of HL in improving health and 'preventing and treating chronic illnesses' [42]. Enhancing health and cancer literacy has the potential to empower individuals to take a more active role in their healthcare, though outcomes will depend on complementary systemic changes (financing, workforce development, organizational reform).

Ultimately, these policies are designed to create a more equitable healthcare system, where individuals are equipped with the knowledge and tools they need to make informed decisions about their health. By fostering a culture of HL, the policies will contribute to better health outcomes, not only for cancer patients but for the population as a whole, as they are intended for all professionals working in the cancer field.

### 4.4 4.4 Strengths and limitations

The current study comes with certain limitations such as that findings are closely connected with Romania's context, policy landscape and health system. As a result, transferability in this format across other countries may be limited. However, many barriers identified and recommendations are common in certain European settings, offering a relevant starting point. The selection of sources in all phases of the project might limit reproducibility, as the desk research was informed by narrative review instead of an exhaustive search of available literature. But this approach offered flexibility for exploring certain areas, highlighting gaps in cancer care and literacy, while providing space to explore emerging theories. Moreso, a facilitator was present during the dialogues, and this might have impacted on the direction of professionals' exchange of information. While this might lead to certain biases, the role of a facilitator was essential to establish a focused discussion and a balance of stakeholder input. Despite efforts to ensure diverse stakeholder representation across both the local and national workshops, certain perspectives may have been underrepresented or absent. These include patients and caregivers with lived experience of cancer (particularly from rural or underserved communities), as well as minority or vulnerable populations, frontline primary care

professionals, and policymakers with direct decision-making authority at the national level.

While formal representation of patients and caregivers was limited, several participants, although attending in their professional or institutional capacity, informally disclosed lived experience as cancer survivors or reported close, long-term professional engagement with people affected by cancer. In addition, patient-related perspectives were further incorporated through oncology patient navigators, representatives of patient advocacy organizations, and through feedback obtained during the external review and co-drafting the policy recommendations from cancer patient advocates and cancer-focused non-governmental organizations. Nevertheless, the limited direct and structured involvement of patients and caregivers in the co-creation workshops remains a key limitation. This may have constrained the depth of patient-centered insights and limited the extent to which the recommendations fully capture the heterogeneity of needs and experiences related to equity in cancer care across Romania. Future policy co-creation initiatives would benefit from more systematic and sustained engagement of patients and caregivers, alongside targeted strategies to include other underrepresented stakeholder groups.

Despite these limitations, the integrative approach of the study offers a valuable foundation for health literacy-informed cancer policy development in Romania. It adds to the limited national resources about health and cancer literacy, positioning these topics at the heart of policy dialogues. The iterative co-drafting process, whereby initial findings from local stakeholder engagement were refined through national-level input and subsequently strengthened by international cancer care and policy experts, ensured that these seven problem areas and their corresponding recommendations were grounded in both local Romanian context and international evidence-informed practice standards. This methodological approach strengthened the credibility and applicability of the resulting policy recommendations. Additionally, it focused on long-term engagement, as many stakeholders got in contact with one another for the first time through this project and turned this opportunity in a continuous collaboration. Moreso, the proposed policies are well aligned with national health strategies that address health literacy, increasing their potential for uptake in practice. Future studies should focus on strategies to include broader subjects related to cancer policies (not just focusing on cancer and health literacy) and a higher and more diverse number of participants by using validated tools, such as WHO EVIPNet Europe Policy Dialogue Preparation and Facilitation Checklist [12] and the SUPPORT Tools (STP 14) [10], which offer a model of reproducibility and good practices that enhance the process by making it rigorous and aligned with international standards.

## 5 Conclusions

This study developed seven evidence-informed policy recommendations with the potential to improve health and cancer literacy and reduce inequities in Romanian cancer care. Through an iterative, participatory process involving local and national stakeholders, policy gaps were identified and translated into actionable recommendations addressing cancer literacy assessment, population-level health education, informal caregiver support, organizational literacy, complementary medicine integration, and survivor

reintegration These recommendations recognize that health literacy must be prioritized across all levels of the healthcare system.

Successful implementation will require sustained multi-stakeholder collaboration, adequate resourcing, realistic timelines, and adaptive management to address institutional capacity constraints. While challenges exist, the comprehensive, co-created nature of these recommendations positions them as a credible foundation for health literacy-informed cancer policy development in Romania and as a model for similar policy-development processes across Europe.

## Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

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**Author contributions**
M.A.C., D.N. (Diana Nemeș) and I.A.C. conceived the study design, prepared the materials, collected the data and drafted the initial manuscript. M.I.U. contributed to methodology and policy development and data collection. E.A.B. and D.N. provided medical expertise in the oncology field, and together with L.C.D. supported the interpretation of findings and the final version of policy recommendations. J.B. contributed to the design of figures and tables, translation and revision of the policy recommendations and proofreading of the manuscript. All authors discussed the results, contributed to the final version, and approved the manuscript.

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**Data availability**
No individual-level or sensitive data was collected as part of this study. Materials generated during the workshops are available upon request.

## Declarations

**Ethics approval and consent to participate**
This work did not involve the collection of individual-level data, personal information, or any form of human subjects research as defined by institutional or national guidelines. The activities conducted were limited to participatory workshops and policy discussions, which did not include data collection, experimentation, or interventions involving human subjects. Therefore, this study was exempt from review by an Institutional Review Board (IRB). According to commonly accepted IRB exemption criteria, such as those outlined in policies regarding educational settings, public behavior observations, or non-identifiable information, no ethical approval was required for the development of this article.

**Competing interests**
The authors declare no competing interests.

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## Publisher's note