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Mapping cancer literacy levels, barriers and facilitators, educational initiatives and misinformation narratives: multiple scoping review protocol

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ABSTRACT

Introduction Cancer literacy (CL) is essential for enabling informed decision-making, prevention, early detection and adherence to treatment. However, disparities in CL across Europe, coupled with the spread of disinformation, limit equitable access to cancer care. This protocol describes a collection of scoping reviews to document the state of CL, misinformation narratives and education and training initiatives and identify barriers and facilitators. This work is embedded within the activities of the Beating Cancer Inequalities through Literacy in Europe project and encompasses nine consortium countries across Europe: Romania, Portugal, Belgium, Bulgaria, Montenegro, Ukraine, Italy, Ireland and Moldova.

Methods and analysis The protocol follows the Joanna Briggs Institute methodology and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews(PRISMA-ScR) checklist, guided by the Population, Concept, Context framework. Searches will be conducted in PubMed, supplemented by grey literature, capturing results from January 2015 to December 2025. Eligible records will undergo full-text review. Data will be extracted into predefined categories reflecting the topics of interest, developed by the research team before extraction to include key study information. Then, sources in local languages are provided by the partners, included and validated by native-speaking team members, adding to the results found by the researchers.

Ethics and dissemination No ethical approval is required. Findings will be disseminated via peer-reviewed publications, project reports and stakeholder workshops.

Study registration Open Science Framework (10.17605/OSF.IO/9AQSX).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The use of the Joanna Briggs Institute scoping review methodology and PRISMA-ScR reporting guidelines ensures a rigorous and transparent methodological framework across all four proposed reviews.
⇒ The integration of multilingual document collection through consortium partners expands coverage beyond English-language databases, reducing language bias.
⇒ Dual independent screening and data extraction with consensus-based conflict resolution minimise selection bias and enhance reliability across reviewers.
⇒ The grey literature search strategy is limited to the first 100 results per source and screened until thematic saturation, which may result in incomplete capture of all relevant non-indexed materials.
⇒ As with all scoping reviews, the study aims to map the breadth and characteristics of the available evidence and does not include a formal critical appraisal of the methodological quality or risk of bias of included sources.

INTRODUCTION

Cancer represents a major public health challenge in Europe, with persistent and well-documented disparities in incidence, mortality, prevention, early detection and treatment outcomes across and within countries.[1] In 2022, an estimated 2.78 million new cancer cases were diagnosed in the in the 27 Member States of the European Union, plus Iceland and Norway, and cancer is projected to become the leading cause of death in Europe by 2035.[2] These inequalities disproportionately affect vulnerable populations, including migrants and individuals with lower educational attainment or socioeconomic status, who experience reduced access to screening, vaccination and early detection services, ultimately leading to poorer outcomes.[3]

In this context, cancer literacy (CL) has emerged as a key concept for understanding and addressing inequities in cancer outcomes. CL refers to the ability to access, understand, appraise and use information related to cancer prevention, diagnosis, treatment, survivorship and care, including the management of late effects.[4] Evidence consistently shows that low levels of CL are associated with delayed diagnosis, suboptimal treatment pathways, limited

engagement in preventive behaviours and poorer quality of life.[5 6] Importantly, CL is considered a modifiable determinant, making it a promising target for public health interventions aimed at reducing cancer-related inequalities.

Despite its relevance, CL levels remain unevenly distributed across Europe. Socioeconomic and regional disparities, as well as cultural, educational and healthcare system-related factors, play a significant role, with Eastern European countries reporting a higher prevalence of low literacy and comparatively limited improvements in cancer mortality over time.[7] These structural and contextual inequalities highlight the need for a systematic understanding of how CL is defined, measured and addressed across different European settings.

In parallel, the contemporary information environment has introduced additional challenges. The spread of cancer-related misinformation can undermine trust in healthcare systems and compromise informed decision-making.[8] Such narratives may disproportionately affect populations with lower literacy levels, further amplifying existing disparities. Addressing these challenges requires not only individual competencies but also cancer-literate organisations and systems capable of supporting critical appraisal of information through education, training and supportive communication environments.[9]

At the policy level, Europe's Beating Cancer Plan and the Cancer Mission provide a coordinated strategic framework to reduce cancer inequalities through actions spanning prevention, early detection, treatment and quality of life.[10] Within this framework, the Beating Cancer Inequalities through Literacy in Europe (CURTAIN) project positions CL as a central lever to reduce inequities, strengthen patient and professional capacities, promote organisational literacy and counter cancer-related disinformation. CURTAIN focuses on nine consortium countries (Romania, Portugal, Belgium, Bulgaria, Montenegro, Ukraine, Italy, Ireland and Moldova) representing diverse health system contexts and levels of cancer burden.[11]

Against this background, there is a clear need for a systematic mapping of the existing evidence on CL in Europe. Specifically, a comprehensive overview is lacking regarding (i) how CL levels are assessed across populations; (ii) the key barriers and facilitators influencing CL at individual, organisational and system levels; (iii) dominant misinformation narratives related to cancer and (iv) existing education and training initiatives targeting CL among patients, healthcare professionals and other stakeholders. Addressing these gaps is essential to inform the design, implementation and evaluation of future CL interventions and to support evidence-based policy and practice across Europe.

Objectives

This protocol aims to map the available evidence on CL in Europe, including literacy levels, key barriers and facilitators, cancer-related misinformation narratives and existing education and training initiatives.

The following are the specific objectives:

- Map the state of CL levels, with a focus on inequalities (urban/rural, vulnerable groups);
- Identify and map key barriers, facilitators and existing gaps in CL.
- Identify and map cancer-related misinformation narratives.
- Map needs, capacities and education and training initiatives in CL.

METHODS AND ANALYSIS

This protocol was registered in Open Science Framework(OSF) (10.17605/OSF.IO/9AQSX).

Review question

What are the levels, barriers, facilitators, misinformation narratives, education and training initiatives related to CL in the European Consortium Countries, and how can they inform the development of effective and equitable CL strategies focused on cancer prevention and care?

Study design

A scoping review methodology was chosen as the most appropriate approach for this study, given the exploratory nature of the research questions and the emerging, heterogeneous body of literature on CL. In addition, scoping reviews aim to map the extent, range and characteristics of available evidence, clarify key concepts and definitions and identify knowledge gaps.[12 13] The CL literature is characterised by variability in conceptual frameworks, study designs, populations and measurement approaches, including the use of both direct and proxy measures. In this context, a scoping review enables a comprehensive overview of how CL has been defined, assessed and operationalised across different settings and stages of the cancer care continuum, without restricting inclusion based on study design or outcome comparability. This approach is consistent with methodological guidance for scoping reviews and reporting recommendations outlined in the PRISMA-ScR.[14]

Beyond its methodological rigour, a defining and distinctive feature of this protocol lies in its coordinating function across nine European consortium countries within the CURTAIN project. The protocol provides an integrated, three-phase methodological framework specifically designed to align distinct national working groups on a complex and multifaceted topic, ensuring absolute consistency and comparability across diverse health system contexts. This represents a concrete operational model for large-scale European multicentre initiatives, which frequently face challenges of fragmented execution and duplicated efforts despite sharing common foundational structures. By establishing a replicable methodological benchmark, this protocol addresses a recognised vulnerability in international collaborative research and offers

Table 1 Population, Concept, Context (PCC) framework for the scoping reviews

Element	Definition
Population (P)	European countries (consortium countries: Romania, Portugal, Belgium, Bulgaria, Montenegro, Ukraine, Italy, Ireland, Moldova), with a focus on vulnerable populations/ groups
Concept (C)	► Cancer literacy levels ► Barriers and facilitators ► Misinformation narratives ► Education and training initiatives
Context (C)	Cancer literacy, cancer prevention and care

a blueprint for future European consortia undertaking similar evidence synthesis endeavours.

Search strategy

The search strategy will be developed and iteratively refined in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews,[15] with input from subject-matter experts within the CURTAIN Consortium to ensure an appropriate balance between sensitivity and specificity. The conduct and reporting of the search process will follow the PRISMA-ScR guidelines.[16]

Bibliographic database search

Electronic searches will be conducted in PubMed using a combination of controlled vocabulary terms, including Medical Subject Headings (MeSH), and free-text keywords, combined through Boolean operators. Search strings will be structured using a modular Population, Concept, Context framework (table 1), as recommended by JBI for scoping reviews. The Population and Context components will be applied consistently across all four scoping reviews, while the Concept component will be adapted to reflect the specific objectives of each review. The scientific literature search will be conducted in English, using predefined and piloted search strategies. The search is planned to be conducted between January and June 2026, and it is expected to include all documents published in English between 1 January 2015 and 31 December 2025. The date of 1 January 2015 was chosen to capture evidence from the most recent decade and reflect current developments in cancer prevention and care. Online supplemental file 1 reports the search queries.

Grey literature and web-based search

To complement bibliographic database searches, a structured web-based search will be undertaken to identify relevant grey literature, including policy documents, reports, guidelines, training programmes and project deliverables. The web screening will target mainly, but will not be limited to, the following sources:

- Institutional and governmental websites, including ministries of health, public health institutes, research councils and regulatory agencies.
- International organisations and European bodies, such as the WHO, the Organisation for Economic Co-operation and Development and the European Commission.
- Professional and scientific associations, non-governmental organisations, civil society groups and patient organisations publishing position papers, reports or educational and training materials relevant to CL.
- Specialised repositories or online platforms hosting project outputs, national strategies and technical or policy reports.

To ensure completeness and contextual relevance, each consortium country will define a list of key institutional and organisational websites. In addition, a complementary search will be performed on Google and ProQuest using predefined keywords and browsing strategies, limited to the first 100 results and screened until thematic saturation is reached.[14] Thematic saturation will be operationalised consistently across all nine consortium countries: screening will continue until at least three consecutive results pages yield no new thematic content not already captured by previous sources; this criterion will be applied independently by the country-responsible partner and verified by a second reviewer. This process will aim to identify country-specific or unpublished materials not captured through predefined sources, while avoiding duplication with bibliographic database searches.

While predefined keywords and search pathways will be applied to enhance consistency, flexibility will be maintained to capture variations in terminology across national, institutional and linguistic contexts.

Multilingual document collection and data management

In parallel with the English-language searches, consortium partners will be invited to identify and collect relevant national or local documents in their respective languages. A standardised data collection form will be used to ensure consistency and comparability across countries and sources.

All retrieved records, both from bibliographic databases and web-based searches, will be screened for relevance against predefined inclusion criteria. Screening and data extraction will be supported by freely available systematic review management software (eg, Rayyan) to enhance transparency, facilitate collaboration among reviewers and document decision-making processes. After removing duplicates, two reviewers will independently screen titles and abstracts, classifying studies as included or excluded. Disagreements will be resolved through discussion, with a third reviewer consulted if consensus cannot be reached.

Full-text screening will follow for all records included at the initial stage. Official documents identified through web searches or provided by partners will be reviewed in parallel by two independent evaluators. The entire

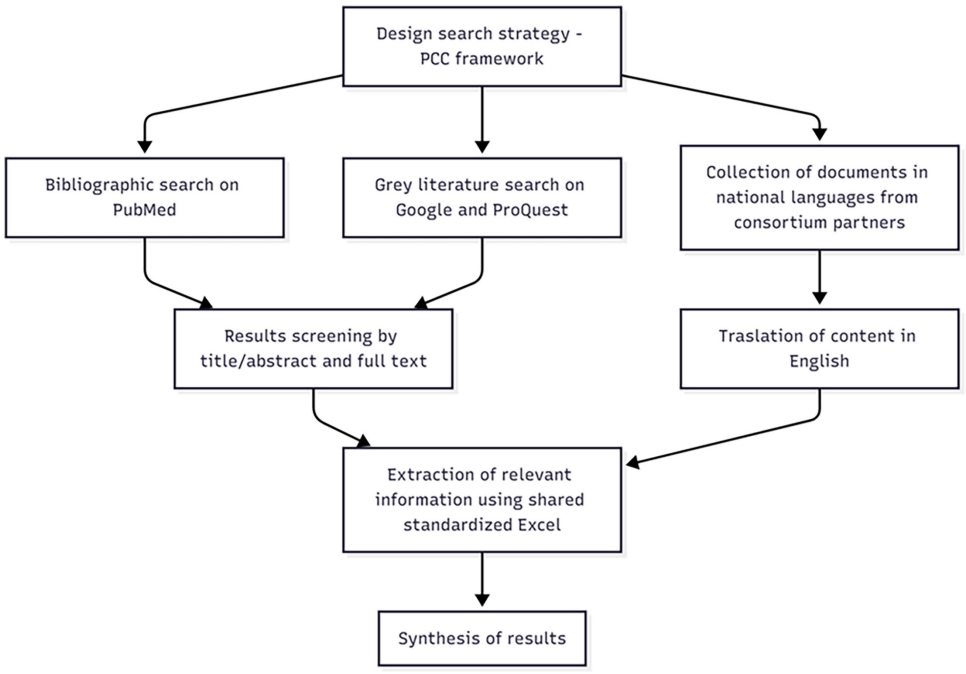

Figure 1 Search strategy flowchart. PCC, Population, Concept, Context.

selection process will be documented in a PRISMA-ScR flowchart.

For documents identified through the English-language searches, key information will be extracted using a predefined Excel-based data extraction form. The data extraction form will be piloted on five full-text documents, comprising a mix of peer-reviewed articles and grey literature sources (eg, policy reports or institutional documents), to ensure the form captures the nuances of both source types and to ensure reliability and consistency among reviewers. Materials collected by consortium partners in national languages will be documented using the same structure, with additional fields capturing language and perceived reliability of the source.

This combined approach, integrating a systematic English-language search with partner-led collection of national-language materials, will ensure comprehensive coverage of both international and country-specific evidence, including policy documents, reports and training initiatives that may not be indexed in bibliographic databases or may use context-specific terminology.

A concise overview of the research strategy is presented in figure 1.

Eligibility criteria

Inclusion criteria

Documents will be considered for inclusion if they meet all the following:

1. Content focus: Address CL, including levels, barriers and facilitators, education or training initiatives, stakeholder engagement or misinformation/disinformation narratives related to cancer prevention, early detection, treatment, survivorship or care.
2. Population and setting: Provide evidence relevant to the general population, patients, caregivers or healthcare professionals in the consortium countries (Romania, Portugal, Belgium, Bulgaria, Montenegro, Ukraine, Italy, Ireland, Moldova) or Europe more broadly.
3. Publication type: Peer-reviewed studies, reports, policy documents, official guidelines, technical reports or other relevant grey literature. Both empirical and conceptual work will be considered.
4. Timeframe: Published from 1 January 2015 onwards to capture recent developments in cancer prevention, care and literacy.
5. Language: Published in English or in the languages of consortium countries; non-English/consortium language documents will be translated or summarised by native-speaking team members.

Exclusion criteria

Documents will be excluded if they meet any of the following:

1. Do not address CL in the context of cancer prevention, detection, treatment, survivorship or care.
2. Published prior to 2015 or unavailable as full text.
3. Focus exclusively on populations or settings outside the consortium countries or Europe.
4. Non-informative formats such as editorials, opinion pieces, conference abstracts without full text or duplicate publications.

Data analysis and presentation

The results will be presented in tables, charts and figures, describing CL in the topics of interest in different countries, focusing on their characteristics and disparities across regions and vulnerable populations.

Data will be synthesised thematically and comparatively, structured by country, target population (general

population, vulnerable groups, patients, healthcare professionals) and type of source (scientific, institutional, grey literature).

As these are scoping reviews, the risk of bias of the included studies will not be assessed.

ETHICS AND DISSEMINATION

These reviews will not involve primary data; ethical approval is not required. Findings will be disseminated through the following:

- Peer-reviewed publications.
- Consortium/projects events/meetings, etc.
- Presentations at scientific and stakeholder meetings.
- Dissemination via CURTAIN digital tools to maximise accessibility and impact.

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