CURTAIN

D2.5 - Comprehensive KPI Report for Cancer Literacy Programs

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Version Tracker

Date	Version number*	Change
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25/02/2026	0.2	Review
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27/02/2026	1	Final version

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List of Abbreviations

- **EU** - European Union
- **GP** - General Practitioner
- **HCP** - Healthcare Professional
- **KPI** - Key Performance Indicator
- **NGO** - Non-Governmental Organisation
- **OECD** - Organisation for Economic Co-operation and Development
- **SME** - Small and Medium-sized Enterprise
- **SMART** - Specific, Measurable, Achievable, Relevant, Time-bound
- **WHO** - World Health Organization
- **WP** - Work Package

Executive Summary

- **Purpose**

Task 2.5 aimed to develop a coherent, evidence-based set of Key Performance Indicators (KPIs) to assess the impact, effectiveness, and equity of cancer literacy programmes implemented across the CURTAIN consortium countries.

- **Objectives and scope of the deliverable**

Under Task 2.5 (WP2), the deliverable aimed to:

- Define core domains for cancer literacy.
- Develop measurable KPIs aligned with identified evidence gaps (Tasks 2.1–2.3).
- Validate and prioritise indicators through expert consultation.

- **Intended audience**

The deliverable is intended for EU and national policy-makers, public health authorities, healthcare professionals, civil society and patient organisations and researchers involved in cancer prevention and care and health literacy.

- **Methodology**

A three-phase approach was applied:

1. Translation of evidence from previous tasks into KPI domains.
2. Multi-country expert focus group with quantitative prioritisation of main domains and KPIs for cancer literacy.
3. Qualitative validation using SMART principles and application of a 40% importance cut-off to define core indicators.

- **Most important findings**

- Strong prioritisation of comprehension and behavioural outcomes, including knowledge of early warning signs, understanding of risk factors, screening uptake, and vaccination initiation.
- Digital literacy and the ability to identify misinformation received the highest overall endorsement.
- Equity-adjusted outreach and disaggregation by vulnerability were widely supported.
- Process-only indicators such as attendance rates were considered less meaningful unless linked to outcomes.

- **Conclusions and main recommendation**

Our work confirms that cancer literacy programmes should be accountable for measurable improvements in understanding, behaviour, digital resilience, and equitable access.

Key recommendations include:

- Adoption of a tiered KPI structure (core and optional indicators).
- Prioritise outcome-oriented and behavioural measures.
- Embed equity and disaggregation as standard practice.
- Integrate misinformation resilience indicators.

Deliverable Introduction

Nowadays cancer is still considered as one of the leading causes of morbidity and mortality in Europe and worldwide, accounting for nearly one in six deaths globally and imposing substantial social, economic, and psychological burdens on individuals and healthcare systems. New technologies and advances in prevention, early detection, diagnosis, and treatment have significantly improved cancer survival rates, although these benefits are not distributed equitably across populations. These differences are not only attributed to biological or healthcare system factors but also to differences in cancer literacy, a factor that focuses on individuals' capacity to understand, evaluate, and use information related to cancer prevention, screening, diagnosis, treatment, survivorship, and palliative care [1,2].

Cancer literacy term includes the knowledge of cancer risk factors, awareness of early warning signs, understanding of screening recommendations and the ability to navigate complex care pathways and treatment decisions. It also refers to skills required to interpret information, such as risks and benefits of screening or treatment options and to engage in shared decision-making with healthcare professionals. Studies have found that low levels of cancer literacy are associated with delayed presentation, reduced participation in screening programs, poorer adherence to treatment, limited engagement in survivorship care, and increased decisional conflict [3,4]. As cancer care becomes increasingly complex, the importance of cancer literacy continues to grow.

In addition, population-based studies have found significant disparities in cancer literacy across socioeconomic status, education level, age, language proficiency and cultural background. Vulnerable populations, such as people with lower educational level, older adults, migrants, and those living in rural or underserved areas, are disproportionately affected by limited cancer literacy [5]. These disparities lead to inequities in cancer outcomes and undermine public health efforts aiming at cancer prevention and early detection. The World Health Organization emphases that improving health literacy is a crucial strategy for reducing health inequalities and strengthening people-centered health systems [6].

Despite the fact that the conceptual and empirical significance of cancer literacy is well established, its integration into healthcare performance assessment is still limited. Traditional metrics mainly focus on clinical outcomes, such as survival rates, stage at diagnosis, treatment completion and complication rates. These indicators may be of great importance, however they do not fully capture patients' ability to understand and act upon cancer-related information, and they do not reflect the quality of communication and support provided to the patients. As a result, there is growing recognition that performance measurement frameworks must incorporate patient-centered and literacy-related dimensions to provide a more comprehensive assessment of cancer care quality.

Key Performance Indicators (KPIs) are structured, measurable metrics used to evaluate the effectiveness, efficiency and quality of healthcare services in relation to defined objectives. In cancer care, KPIs are widely developed to monitor screening, diagnostic timeliness, treatment pathways and outcomes across the cancer continuum. However, most existing KPIs give emphasis at the system performance rather than patient capability, leaving an important gap in understanding how well the system supports individuals comprehension and engagement throughout their cancer journey [7].

By integrating cancer literacy into KPI frameworks, we aim at significantly bridging this gap. Cancer literacy-related KPIs can be designed to assess both individual-level outcomes and organizational practices, such as patient understanding of screening results, clarity of treatment information, use of plain language and decision aids and patient-reported confidence in managing cancer-related decisions. In addition, KPIs may include the % of patients who demonstrate adequate understanding of their diagnosis and treatment pathway, or patient-reported measures of communication quality during oncology consultations. Such KPIs align with broader quality frameworks that emphasize on the patient-centered care, shared decision-making and equity.

From a public health perspective, cancer literacy KPIs can support population-level monitoring and evaluation of cancer control strategies. For example, screening programs depend on individuals' understanding of cancer risk, benefits and harms of screening and follow-up procedures. KPIs that capture informed participation, comprehension of screening results and adherence to follow-up recommendations provide valuable insights beyond crude participation rates. Such measures can inform targeted interventions aimed at improving communication strategies and reducing disparities in screening uptake and outcomes [8].

Finally, the integration of cancer literacy KPIs also aligns with international calls for learning health systems and accountability in cancer care. Organizations such as the Organisation for Economic Co-operation and Development highlight the need for patient-reported indicators and literacy measures to enhance transparency, comparability and continuous improvement in healthcare performance [9]. By including cancer literacy within KPI frameworks, we can move toward more holistic assessments of quality that recognize the central role of patient understanding and engagement in achieving optimal cancer outcomes.

Deliverable objective and scope

Task 2.5 aimed to develop a coherent, evidence-based set of Key Performance Indicators (KPIs) to assess the impact, effectiveness, and equity of cancer literacy programmes implemented across the CURTAIN consortium countries. These KPIs are grounded in the findings of Tasks 2.1 (Mapping of cancer literacy resources), 2.2 (Stakeholder mapping), and 2.3 (Best practices and initiative identification). The final KPIs support monitoring of outreach, accessibility, knowledge retention, behavioural change, and community-level health outcomes.

Objectives

Translate gaps, needs, and opportunities identified in Tasks 2.1–2.3 into measurable monitoring domains.

Engage stakeholders (policy makers, healthcare professionals, NGOs, patient organisations, digital platforms) to validate KPI domains through a structured focus group

Develop **SMART-aligned KPIs that measure:** Reach & engagement, Comprehension & knowledge gain, Behavioural intention & change, Health System & Empowerment KPIs, Digital/health literacy skills, Trust & misinformation resilience

Produce a **KPI Report** to guide future monitoring within CURTAIN and support scalability across EU Member States.

Relation to other WPs and deliverables

The deliverable is conducted within the WP2, complementing the tasks 2.1, 2.2 and 2.3. The present deliverable is linked with:

- The WP3 (Design of the cancer literacy tools and interventions) – D3.1 (Curriculums of the educational courses prepared in the frame of the WP).

- The WP5 (Cancer literacy education of Health Care Professionals and relevant stakeholders) – Task 5.1 (Training the health care professionals and key stakeholders for cancer literacy: pilot the Flagship European Cancer Health Literacy Training Programme) and Task 5.3 (Improvement of the Flagship European Cancer Health Literacy Training Programme based on evaluation recommendations)
- The WP6 (Developing a Virtual Cancer Literacy Library and Policy Guidelines for Cancer Literacy) – D6.3 (Report on the Roadmap for the Capacity Building training on Cancer Health Literacy for European countries).

Content of the deliverable

This deliverable includes the following key components:

- **Introduction and Background**
  - Overview of cancer literacy.
  - Rationale for integrating cancer literacy into performance measurement frameworks.

- **Objective and Scope of Task 2.5**
  - Development of a structured KPI framework to monitor impact, effectiveness, and equity of cancer literacy programmes.
  - Alignment with findings from Tasks 2.1, 2.2, and 2.3

- **Methodology**
  - Organisation and implementation of a multi-country expert focus group.
  - Quantitative prioritisation of KPIs
  - Qualitative validation using SMART principles (Specific, Measurable, Achievable, Relevant, Time-bound).
  - Application of a 40% importance cut-off to distinguish core and optional KPIs.

- **Results of the Focus Group**
  - Prioritisation of accountability domains such as awareness, behavioural engagement, misinformation resilience.
  - Ranking of KPI domains (reach, engagement, comprehension, behavioural change, empowerment, digital literacy).
  - Domain-by-domain analysis of proposed KPIs.
  - Identification and removal of overlapping or lower-priority KPIs.

- **Validated KPI Framework**
  - Structured list of KPIs with >40% importance (core indicators).
  - List of KPIs with <40% importance (optional indicators).
  - Cross-cutting KPIs addressing equity, sustainability and scalability.

- **Conclusions and Main Recommendations**
  - Summary of key findings and consensus areas.
  - Recommendations for adoption of a tiered KPI model.
  - Guidance for implementation, reporting and policy alignment.

Methodology

Phase 1 – Translation of Findings into KPI Domains

Using outputs from Tasks 2.1–2.3:

- We identified **core literacy dimensions** (availability, accessibility, comprehensibility, relevance, cultural adequacy).
- Extracted priority gaps (misinformation patterns, linguistic barriers, digital divide, low awareness of screening).
- Defined 6 preliminary KPI domains such as:
  - Reach and dissemination
  - Comprehension and knowledge gain
  - Digital/health literacy skills
  - Trust and misinformation resilience
  - Behavioural change
  - Equity and inclusion
- Prepared a set of KPIs per domain

Phase 2 — Stakeholder Focus Group

Purpose: The aim of the focus group was to validate the KPI domains, refine indicators, and identify contextual needs across regions.

Participants:
A two-hours focus groups was conducted on the 20th January 2026. Twenty experts representing a diverse mix of countries and stakeholder sectors. By country, participants were distributed as follows: Portugal (4), Romania (4), Italy (3), Bulgaria (2), International (4), Ukraine (1), Montenegro (1), Belgium (1). Regarding stakeholder type, the group included academia (6), public health agencies (6), civil society (3), healthcare professionals (2), and SMEs (2), and citizens/patients/civil society (1). This composition ensured a balance of perspectives across both geographic regions and professional backgrounds, enabling a comprehensive discussion of the topic under study.

Stakeholders were provided with an invitation and gave their consent to participate verbally at the beginning of the recorded meeting. They were informed that their responses will be used for project purposes and to produce this public deliverable.

Methodological Approach:

A semi-structured facilitation using guiding questions was used for the focus group discussion. The methodology used in this focus group resembled elements of the Delphi technique, a structured method for building expert consensus [10]. Similar to Delphi techniques, participants independently rated predefined indicators, results were aggregated quantitatively, reviewed and refined priorities based on structured discussion. Although this process was conducted within a single focus group session, it incorporated core Delphi principles, including systematic expert judgement, controlled feedback and progressive refinement of indicators. For this reason, the approach may be considered a structured consensus-building exercise informed by Delphi methodology. The moderator presented the results of the Tasks 2.1 to 2.3, followed by a real time mapping exercise of the significant domains and proposed KPIs. This exercise was supported by a set of 10 poll questions.

A structured polling process was conducted during the focus group to prioritise key performance indicators (KPIs) for cancer literacy programmes across predefined domains. Participants were asked either respond to multiple choice questions where they could select 2-3 of the most or least important cancer literacy domains or to rate the relative importance of proposed KPIs using a five-point Likert scale, where 1 indicated *low importance* and 5 indicated *high importance*. For selected sections addressing accountability and aspirational outcomes, participants instead selected a limited number of domains they considered most relevant, and results were expressed as proportions of total respondents.

Outputs:

- Refined KPI domains
- Identified measurement challenges and required data sources

Phase 3 - Qualitative Validation of KPIs and Cut-off Definition

Following the quantitative prioritisation of KPIs, a structured group exercise was conducted to assess whether the proposed indicators met core quality criteria required for inclusion in a cancer literacy KPI framework. This exercise was explicitly framed as a principle-based validation, rather than a formal feasibility or implementation assessment, in order to avoid premature measurement pressure on participants.

Participants were asked to assess, in principle, whether the prioritised KPIs satisfied the following five criteria:

- **Specific**: Clearly linked to defined cancer literacy outcomes rather than broad or diffuse programme goals.
- **Measurable**: Amenable to quantitative and/or qualitative measurement using indicators with clear and interpretable descriptors.
- **Achievable**: Realistically measurable within existing national systems, project-level infrastructure, or routine programme implementation contexts.
- **Relevant**: Directly addressing the evidence gaps and priority needs identified in earlier project tasks (Tasks 2.1–2.3).
- **Time-bound**: Suitable for assessment within predefined or reasonably specified measurement intervals (e.g. post-intervention, short-term follow-up).

These criteria were selected to align with established indicator development principles while remaining adaptable to the diverse settings in which cancer literacy programmes are implemented.

Participants reviewed the KPI set and discussed alignment with each criterion at a conceptual level. The objective was not to reach unanimous agreement on every indicator, but to identify whether KPIs were, in principle, fit for purpose within a future measurement framework. Contributions from this exercise were collected to inform the refinement of KPI definitions and supported the distinction between core and optional indicators identified through the quantitative cut-off process.

Aggregation of Importance Scores

For Likert-scale items, KPI importance was operationalised as the proportion of respondents assigning a rating of **4 (important)** or **5 (very important)**. These responses were aggregated and expressed as percentages of total valid responses per KPI.

Rationale for the 40% Cut-off

A **40% importance threshold** was applied to distinguish between *prioritised* and *non-prioritised* KPIs. KPIs endorsed by at least 40% of participants were classified as having **high perceived importance**, reflecting a minimum level of consensus within a heterogeneous expert group. This threshold was selected to balance inclusivity with discrimination, allowing for the retention of indicators demonstrating broad relevance while excluding those with limited support.

The cut-off also aligns with the exploratory and consensus nature of the focus group, where absolute agreement was neither expected nor required. KPIs falling below the 40% threshold were retained for transparency but classified separately as **lower-priority indicators**, acknowledging their potential contextual relevance without positioning them as core elements of the proposed framework (Presented in Results section).

Classification of KPIs

Following application of the cut-off, KPIs were grouped into two categories:

1. **KPIs with >40% importance**, considered suitable for inclusion in a validated menu of core indicators for cancer literacy programmes.
2. **KPIs with <40% importance**, considered optional indicators at this stage.

This classification informed subsequent synthesis of the KPI framework and supported transparent reporting of both consensus and divergence among participants.

Results of the focus group

Table 1: Alignment: What should cancer literacy programmes be held accountable for?

Domain	Results
Awareness & understanding	21/29 (72%)
Trust & confidence	17/29 (59%)
Engagement with prevention or screening	19/29 (66%)
Ability to navigate the system	11/29 (38%)
Resistance to misinformation	22/29 (76%)

Participants were asked to select up to three domains for which cancer literacy programmes should be considered non-negotiable accountable for. Resistance to misinformation was also among the most frequently selected domain (76%), followed by awareness and understanding (72%) and engagement with prevention or screening (66%). Trust and confidence were also selected by most participants (59%), while ability to navigate the health system received the lower endorsement (38%). Overall, the findings indicate that participants primarily conceptualised cancer literacy programmes as mechanisms for strengthening cognitive understanding and protecting against misinformation.

Table 2: Which are aspirational but still important?

Domain	Results
Awareness & understanding	3/19 (16%)
Trust & confidence	10/19 (53%)
Engagement with prevention or screening	9/19 (47%)
Ability to navigate the system	11/19 (58%)
Resistance to misinformation	6/19 (32%)

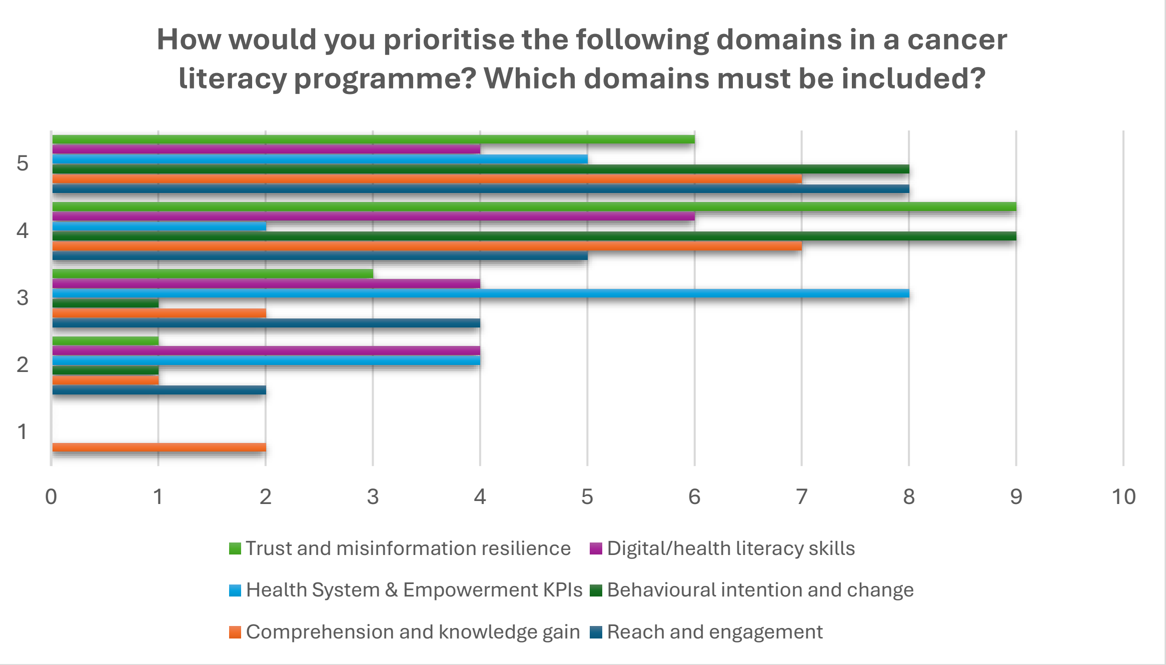
When participants were asked to identify up to two domains considered aspirational rather than core, ability to navigate the health system was most frequently selected (58%), followed by trust and confidence (53%) and engagement with prevention or screening (47%). In contrast, resistance to misinformation (32%) and particularly awareness and understanding (16%) were less often selected as aspirational, suggesting that these domains were more widely perceived as essential components of cancer literacy programmes.

Prioritising KPI domains

Table 3: Prioritising KPI domains

Domain	1	2	3	4	5	No. of answers
Reach and engagement	0 (0%)	2 (11%)	4 (21%)	5 (26%)	8 (42%)	19
Comprehension and knowledge gain	2 (11%)	1 (5%)	2 (11%)	7 (37%)	7 (37%)	19
Behavioural intention and change	0 (0%)	1 (5%)	1 (5%)	9 (47%)	8 (42%)	19
Health System & Empowerment KPIs	0 (0%)	4 (21%)	8 (42%)	2 (11%)	5 (26%)	19
Digital/health literacy skills	1 (5%)	4 (21%)	4 (21%)	6 (32%)	4 (21%)	19
Trust and misinformation resilience	0 (0%)	1 (5%)	3 (16%)	9 (47%)	6 (32%)	19

Figure 1: Prioritising KPI domains



Using a five-point Likert scale, participants prioritised behavioural intention and change and comprehension and knowledge gain as the most important KPI domains, with the highest concentration of ratings at levels 4 and 5. Trust and misinformation resilience was also consistently rated as highly important. Health system and empowerment KPIs showed a broader distribution of responses, with a substantial proportion of mid-range ratings, while digital and health literacy skills were considered important but not consistently prioritised at the highest level relative to other domains.

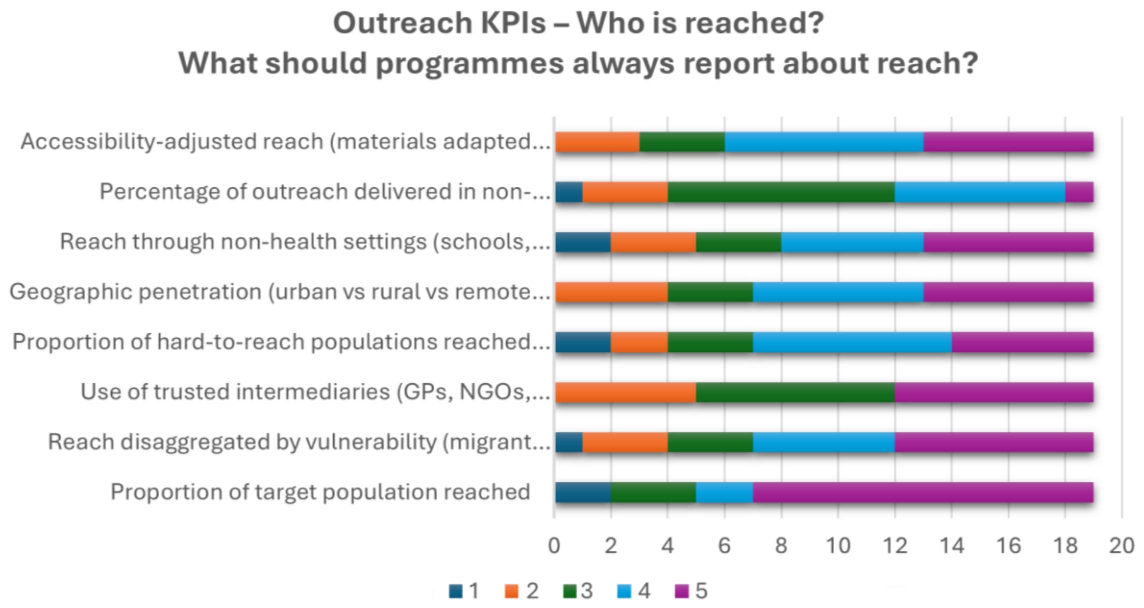
KPI generation – Domain by domain

A. Outreach KPIs – Who is reached?

Table 4: A. Outreach KPIs – Who is reached?

Domain	1	2	3	4	5	No. of answers
Proportion of target population reached	2 (11%)	0 (0%)	3 (16%)	2 (11%)	12 (63%)	19
Reach disaggregated by vulnerability (migrant status, rurality, gender)	1 (5%)	3 (16%)	3 (16%)	5 (26%)	7 (37%)	19
Use of trusted intermediaries (GPs, NGOs, community orgs)	0 (0%)	5 (26%)	7 (37%)	0 (0%)	7 (37%)	19
Proportion of hard-to-reach populations reached relative to their population share	2 (11%)	2 (11%)	3 (16%)	7 (37%)	5 (26%)	19
Geographic penetration (urban vs rural vs remote coverage index)	0 (0%)	4 (21%)	3 (16%)	6 (32%)	6 (32%)	19
Reach through non-health settings (schools, workplaces, religious/community centres)	2 (11%)	3 (16%)	3 (16%)	5 (26%)	6 (32%)	19
Percentage of outreach delivered in non-dominant or minority languages	1 (5%)	3 (16%)	8 (42%)	6 (32%)	1 (5%)	19
Accessibility-adjusted reach (materials adapted for low literacy, disability, or cultural relevance)	0 (0%)	3 (16%)	3 (16%)	7 (37%)	6 (32%)	19

Figure 2: A. Outreach KPIs – Who is reached?



Among outreach-related indicators, the proportion of the target population reached was rated as highly important, with 63% of respondents assigning the highest importance score. Indicators related to geographic penetration and reach among vulnerable or hard-to-reach populations, were also strongly prioritised. In contrast, the percentage of outreach delivered in non-dominant or minority languages received a greater concentration of mid-range ratings, indicating more varied perceptions regarding its importance.

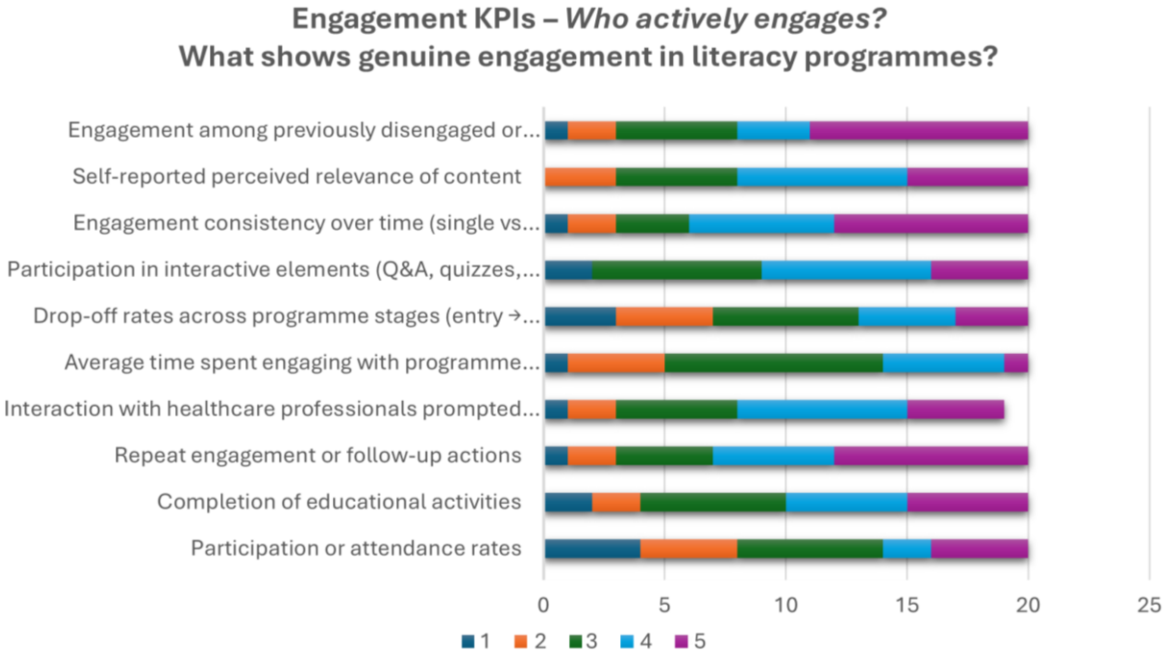
B. Engagement KPIs – Who actively engages?

Table 5: B. Engagement KPIs – Who actively engages?

Domain	1	2	3	4	5	No. of answers
Participation or attendance rates	4 (20%)	4 (20%)	6 (30%)	2 (10%)	4 (20%)	20
Completion of educational activities	2 (10%)	2 (10%)	6 (30%)	5 (25%)	5 (25%)	20
Repeat engagement or follow-up actions	1 (5%)	2 (10%)	4 (20%)	5 (25%)	8 (40%)	20
Interaction with healthcare professionals prompted by programme	1 (5%)	2 (11%)	5 (26%)	7 (37%)	4 (21%)	19

Average time spent engaging with programme materials or sessions	1 (5%)	4 (20%)	9 (45%)	5 (25%)	1 (5%)	20
Drop-off rates across programme stages (entry → completion)	3 (15%)	4 (20%)	6 (30%)	4 (20%)	3 (15%)	20
Participation in interactive elements (Q&A, quizzes, peer discussion)	2 (10%)	0 (0%)	7 (35%)	7 (35%)	4 (20%)	20
Engagement consistency over time (single vs sustained engagement)	1 (5%)	2 (10%)	3 (15%)	6 (30%)	8 (40%)	20
Self-reported perceived relevance of content	0 (0%)	3 (15%)	5 (25%)	7 (35%)	5 (25%)	20
Engagement among previously disengaged or sceptical participants	1 (5%)	2 (10%)	5 (25%)	3 (15%)	9 (45%)	20

Figure 3: B. Engagement KPIs – Who actively engages?



Indicators reflecting repeat engagement and engagement consistency over time received the highest levels of prioritisation, with the largest proportion of ratings at the maximum importance level. Engagement among previously disengaged or skeptical participants was also considered highly important. More conventional indicators, such as participation or attendance rates, demonstrated wider dispersion across the Likert scale and lower concentrations of top-tier ratings, suggesting these were viewed as less indicative of meaningful engagement.

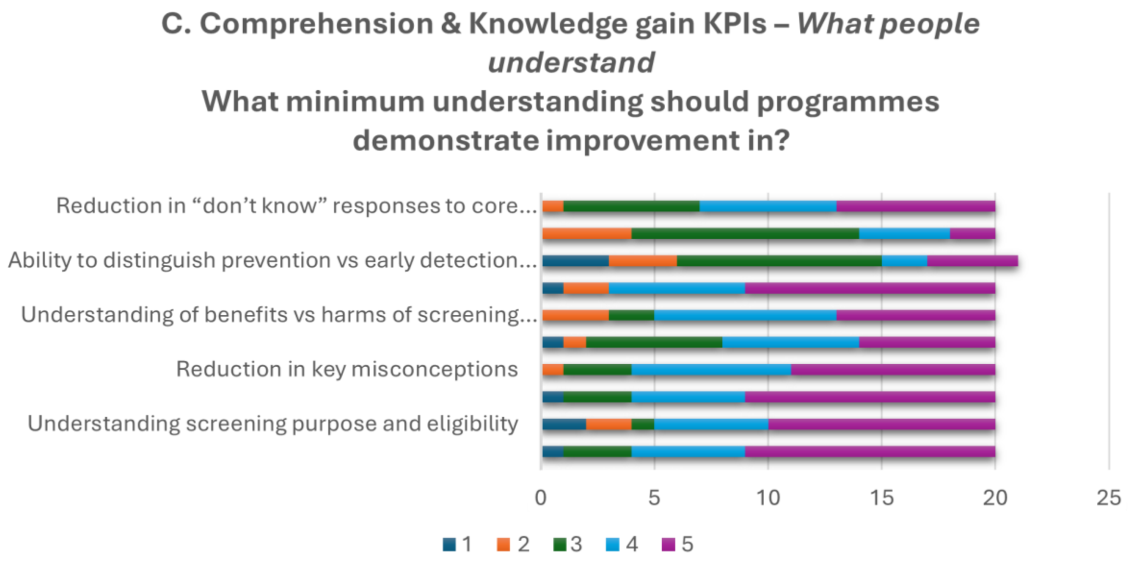
C. Comprehension & Knowledge gain KPIs – What people understand

Table 6: C. Comprehension & Knowledge gain KPIs – What people understand

Domain	1	2	3	4	5	No. of answers
Understanding of modifiable cancer risks	1 (5%)	0 (0%)	3 (15%)	5 (25%)	11 (55%)	20
Understanding screening purpose and eligibility	2 (10%)	2 (10%)	1 (5%)	5 (25%)	10 (50%)	20
Awareness of prevention and vaccination benefits	1 (5%)	0 (0%)	3 (15%)	5 (25%)	11 (55%)	20
Reduction in key misconceptions	0 (0%)	1 (5%)	3 (15%)	7 (35%)	9 (45%)	20
Ability to correctly interpret personal cancer risk scenarios	1 (5%)	1 (5%)	6 (30%)	6 (30%)	6 (30%)	20
Understanding of benefits vs harms of screening (overdiagnosis, false positives)	0 (0%)	3 (15%)	2 (10%)	8 (40%)	7 (35%)	20
Knowledge of early warning signs that require medical attention	1 (5%)	2 (10%)	0 (0%)	6 (30%)	11 (55%)	20
Ability to distinguish prevention vs early detection concepts	3 (14%)	3 (14%)	9 (43%)	2 (10%)	4 (19%)	21
Self-rated confidence in	0 (0%)	4 (20%)	10 (50%)	4 (20%)	2 (10%)	20

explaining cancer risks to others						
Reduction in “don’t know” responses to core cancer literacy questions	0 (0%)	1 (5%)	6 (30%)	6 (30%)	7 (35%)	20

Figure 4: C. Comprehension & Knowledge gain KPIs – What people understand



The highest-rated indicators in this domain related to understanding modifiable cancer risk factors, awareness of prevention and vaccination benefits, and knowledge of early warning signs requiring medical attention. Indicators such as ability to distinguish prevention from early detection and self-rated confidence in explaining cancer risks to others were more frequently assigned mid-range importance scores, reflecting greater uncertainty regarding their prioritisation or measurement relevance.

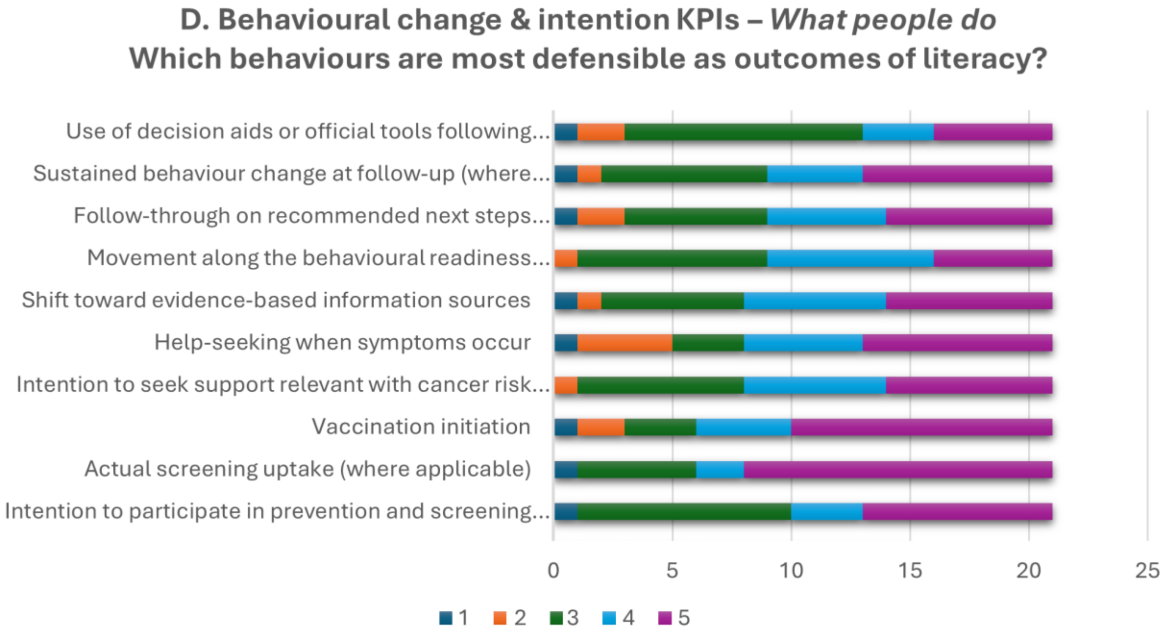
D. Behavioural change & intention KPIs – What people do

Table 7: D. Behavioural change & intention KPIs – What people do

Domain	1	2	3	4	5	No. of answers
Intention to participate in prevention and screening programs	1 (5%)	0 (0%)	9 (43%)	3 (14%)	8 (38%)	21
Actual screening uptake (where applicable)	1 (5%)	0 (0%)	5 (24%)	2 (10%)	13 (62%)	21

Vaccination initiation	1 (5%)	2 (10%)	3 (14%)	4 (19%)	11 (52%)	21
Intention to seek support relevant with cancer risk factor (e.g. smoking cessation)	0 (0%)	1 (5%)	7 (33%)	6 (29%)	7 (33%)	21
Help-seeking when symptoms occur	1 (5%)	4 (19%)	3 (14%)	5 (24%)	8 (38%)	21
Shift toward evidence-based information sources	1 (5%)	1 (5%)	6 (29%)	6 (29%)	7 (33%)	21
Movement along the behavioural readiness spectrum (e.g. precontemplation → action)	0 (0%)	1 (5%)	8 (38%)	7 (33%)	5 (24%)	21
Follow-through on recommended next steps (booking appointments, requesting info)	1 (5%)	2 (10%)	6 (29%)	5 (24%)	7 (33%)	21
Sustained behaviour change at follow-up (where feasible)	1 (5%)	1 (5%)	7 (33%)	4 (19%)	8 (38%)	21
Use of decision aids or official tools following participation	1 (5%)	2 (10%)	10 (48%)	3 (14%)	5 (24%)	21

Figure 5: D. Behavioural change & intention KPIs – What people do



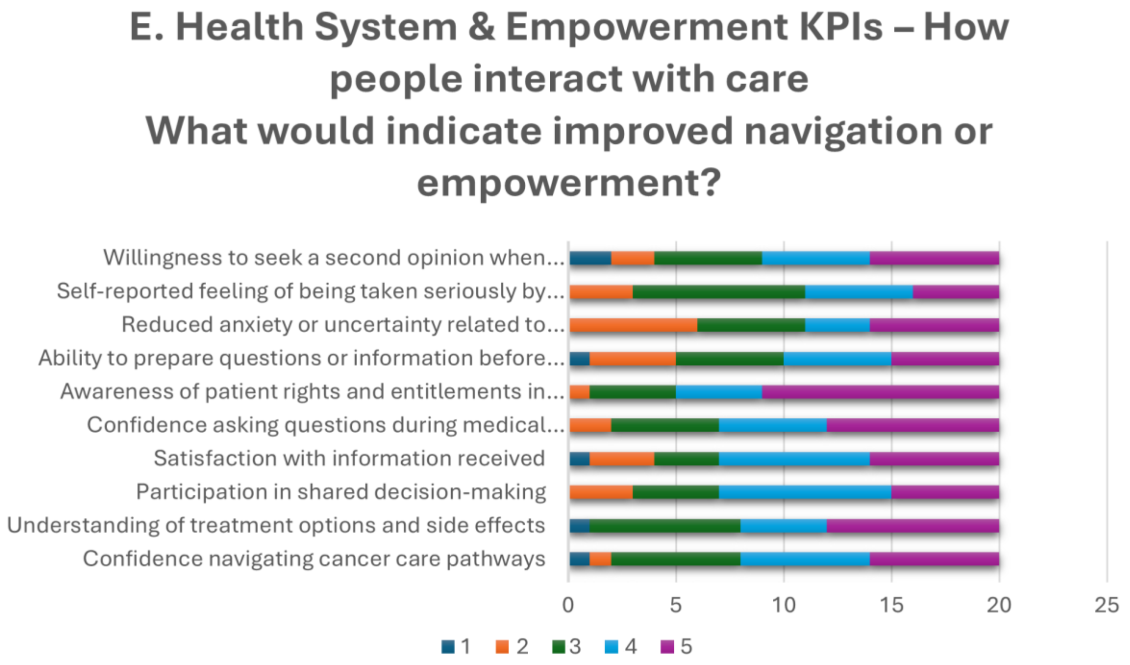
Actual screening uptake, where applicable, and vaccination initiation were rated as the most defensible behavioural outcomes of cancer literacy programmes, with the majority of participants giving high importance scores. Indicators related to intentions (e.g. intention to participate in prevention or screening programmes) and follow-through on recommended actions also received strong support. Measures of sustained behaviour change over time were viewed as important but demonstrated a wider spread of ratings, likely reflecting perceived feasibility constraints.

E. Health System & Empowerment KPIs – How people interact with care

Table 8: E. Health System & Empowerment KPIs – How people interact with care

Domain	1	2	3	4	5	No. of answers
Confidence navigating cancer care pathways	1 (5%)	1 (5%)	6 (30%)	6 (30%)	6 (30%)	20
Understanding of treatment options and side effects	1 (5%)	0 (0%)	7 (35%)	4 (20%)	8 (40%)	20
Participation in shared decision-making	0 (0%)	3 (15%)	4 (20%)	8 (40%)	5 (25%)	20
Satisfaction with information received	1 (5%)	3 (15%)	3 (15%)	7 (35%)	6 (30%)	20
Confidence asking questions during medical consultations	0 (0%)	2 (10%)	5 (25%)	5 (25%)	8 (40%)	20
Awareness of patient rights and entitlements in cancer care	0 (0%)	1 (5%)	4 (20%)	4 (20%)	11 (55%)	20
Ability to prepare questions or information before appointments	1 (5%)	4 (20%)	5 (25%)	5 (25%)	5 (25%)	20
Reduced anxiety or uncertainty related to navigating cancer services	0 (0%)	6 (30%)	5 (25%)	3 (15%)	6 (30%)	20
Self-reported feeling of being taken seriously by healthcare providers	0 (0%)	3 (15%)	8 (40%)	5 (25%)	4 (20%)	20
Willingness to seek a second opinion when appropriate	2 (10%)	2 (10%)	5 (25%)	5 (25%)	6 (30%)	20

Figure 6: E. Health System & Empowerment KPIs – How people interact with care



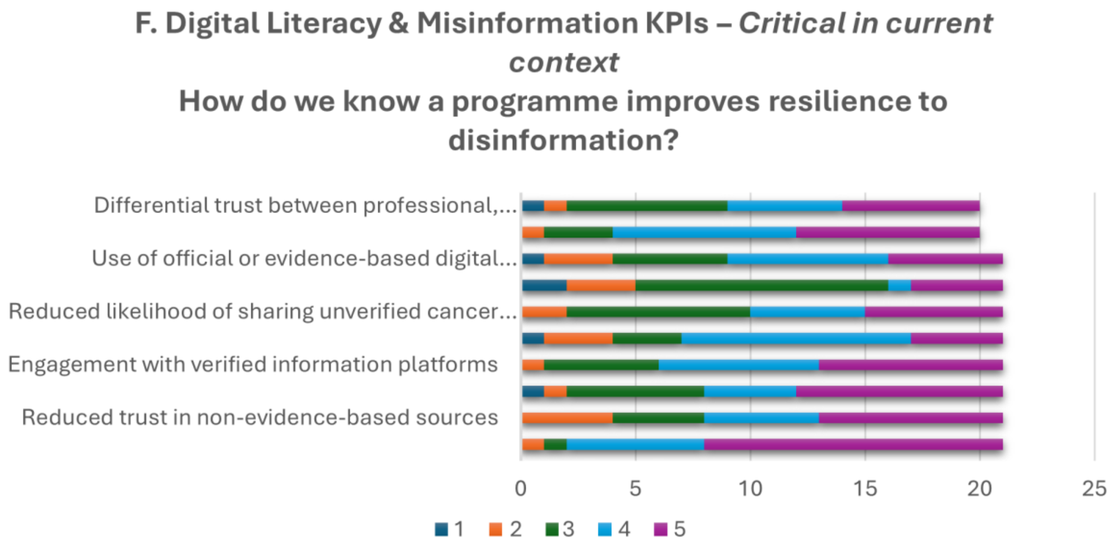
Participants assigned high importance to indicators reflecting awareness of patient rights and entitlements, confidence asking questions during medical consultations and understanding treatment options and side effects. Measures related to reduced anxiety when navigating cancer services and willingness to seek a second opinion showed greater variability in importance ratings, indicating less consensus across participants.

F. Digital Literacy & Misinformation KPIs – Critical in current context

Table 9: F. Digital Literacy & Misinformation KPIs – Critical in current context

Domain	1	2	3	4	5	No. of answers
Ability to identify false or misleading claims	0 (0%)	1 (5%)	1 (5%)	6 (29%)	13 (62%)	21
Reduced trust in non-evidence-based sources	0 (0%)	4 (19%)	4 (19%)	5 (24%)	8 (38%)	21
Increased trust in healthcare professionals	1 (5%)	1 (5%)	6 (29%)	4 (19%)	9 (43%)	21
Engagement with verified information platforms	0 (0%)	1 (5%)	5 (24%)	7 (33%)	8 (38%)	21
Recognition of emotional manipulation or conspiracy framing	1 (5%)	3 (14%)	3 (14%)	10 (48%)	4 (19%)	21
Reduced likelihood of sharing unverified cancer information	0 (0%)	2 (10%)	8 (38%)	5 (24%)	6 (29%)	21
Awareness of how algorithms influence health information exposure	2 (10%)	3 (14%)	11 (52%)	1 (5%)	4 (19%)	21
Use of official or evidence-based digital resources after intervention	1 (5%)	3 (14%)	5 (24%)	7 (33%)	5 (24%)	21
Confidence reporting or challenging misinformation	0 (0%)	1 (5%)	3 (15%)	8 (40%)	8 (40%)	20
Differential trust between professional, institutional, and peer sources	1 (5%)	1 (5%)	7 (35%)	5 (25%)	6 (30%)	20

Figure 7: Digital Literacy & Misinformation KPIs – Critical in current context



Within the digital literacy domain, ability to identify false or misleading claims received the strongest endorsement, with over 60% of participants assigning the highest importance score. Increased trust in healthcare professionals and engagement with verified information platforms were also highly prioritised. In contrast, awareness of algorithmic influence on health information exposure was more frequently rated at moderate importance levels, suggesting lower prioritisation relative to more directly observable outcomes.

Cross-Cutting KPIs

Table 10: Cross-Cutting KPIs

Domain	1	2	3	4	5	No. of answers
Equity impact score (gap reduction between vulnerable and general populations)	0 (0%)	2 (12%)	3 (18%)	5 (29%)	7 (41%)	17
Sustainability of outcomes (persistence over time)	0 (0%)	0 (0%)	4 (24%)	4 (24%)	9 (53%)	17
Participant-perceived usefulness for real-life decisions	1 (6%)	2 (12%)	6 (35%)	3 (18%)	5 (29%)	17
Scalability and transferability across settings or countries	0 (0%)	3 (18%)	5 (29%)	5 (29%)	4 (24%)	17
Burden of measurement vs value generated	3 (18%)	2 (12%)	4 (24%)	4 (24%)	4 (24%)	17

Figure 8: Cross-Cutting KPIs

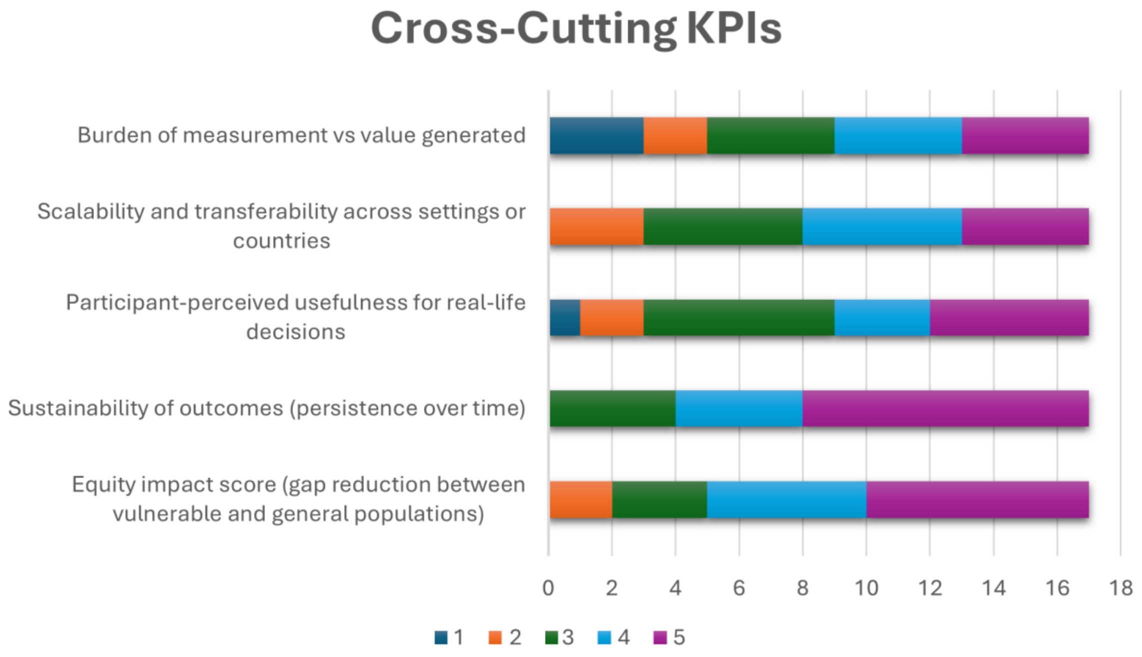


Table 11: KPI Prioritisation Using a 40% Importance Cut-off

Below are structured KPI lists for each table, applying a 40% cut-off for importance, defined as ≥40% of respondents rating the KPI as "important" or "very important" (Likert 4–5 combined).

KPIs with >40% Importance

Domain	KPI	%
A. Outreach	Proportion of target population reached	74%
	Accessibility-adjusted reach	69%
	Geographic penetration	64%
	Reach disaggregated by vulnerability	63%
	Reach through non-health settings	58%
B. Engagement	Repeat engagement or follow-up actions	65%
	Engagement among previously disengaged or sceptical participants	60%
	Self-reported perceived relevance of content	60%
	Interaction with healthcare professionals prompted by programme	58%
	Participation in interactive elements	55%
	Completion of educational activities	50%

C. Comprehension & Knowledge Gain	Knowledge of early warning signs requiring medical attention	85%
	Understanding modifiable cancer risks	80%
	Awareness of prevention and vaccination benefits	80%
	Reduction in key misconceptions	80%
	Understanding benefits vs harms of screening	75%
	Reduction in “don’t know” responses	65%
	Ability to correctly interpret personal cancer risk scenarios	60%
D. Behavioural Change & Intention	Actual screening uptake	72%
	Vaccination initiation	71%
	Intention to seek support for cancer risk factors	62%
	Help-seeking when symptoms occur	62%
	Shift toward evidence-based information sources	62%
	Sustained behaviour change at follow-up	57%
	Follow-through on recommended next steps	57%
	Intention to participate in prevention or screening	52%
E. Health System & Empowerment	Awareness of patient rights and entitlements	75%
	Participation in shared decision-making	65%
	Satisfaction with information received	65%
	Confidence asking questions during medical consultations	65%
	Understanding treatment options and side effects	60%
	Confidence navigating cancer care pathways	60%
	Willingness to seek a second opinion	55%
	Reduced anxiety navigating cancer services	45%
	Feeling taken seriously by healthcare providers	45%
F. Digital Literacy & Misinformation	Ability to identify false or misleading claims	91%
	Confidence reporting or challenging misinformation	80%
	Recognition of emotional manipulation or conspiracy framing	67%
	Increased trust in healthcare professionals	62%

	Use of official or evidence-based digital resources	57%
	Differential trust across information sources	55%
	Reduced likelihood of sharing unverified information	53%

KPIs with <40% Importance

Domain	KPI	%
A. Outreach	Use of trusted intermediaries	37%
	Percentage of outreach delivered in non-dominant or minority languages	37%
B. Engagement	Drop-off rates across programme stages	35%
	Participation or attendance rates	30%
	Average time spent engaging with programme materials	30%
C. Comprehension & Knowledge Gain	Self-rated confidence explaining cancer risks to others	30%
	Ability to distinguish prevention vs early detection concepts	29%
D. Behavioural Change & Intention	Use of decision aids or official tools	38%
F. Digital Literacy & Misinformation	Awareness of algorithmic influence on information exposure	24%

Focus group experts identified some similar of overlapping KPIs per domain and discussion led to the exclusion of some initially proposed or they were underscored and marked as non-essential (<40% importance), as follows:

Overlapping / similar meaning clusters

During the focus group, several KPIs were identified as conceptually overlapping and were grouped into clusters to reduce redundancy and improve conceptual clarity.

Within **Outreach KPIs**, under *Equity and vulnerability reach*, “reach disaggregated by vulnerability” was retained as the core indicator while “proportion of hard-to-reach populations reached relative to their population share” was excluded due to conceptual overlap. Under *Accessibility and inclusion*, “accessibility-adjusted reach (low literacy, disability, cultural relevance)” was retained, whereas “percentage of outreach delivered in non-dominant or minority languages” was excluded. However, having been rated below the 40% importance threshold, it was retained only within the non-essential KPI set.

Within **Engagement KPIs**, in the cluster addressing *participation depth*, “participation in interactive elements” was retained as the strongest indicator of intensified engagement, while “participation or attendance rates” and “average time spent engaging” were excluded, both having received less than 40% importance and retained as non-essential indicators. In the *retention and continuity* cluster, “repeat engagement or follow-up actions” was maintained as the most outcome-oriented indicator of sustained engagement, whereas “engagement consistency over time” and “drop-off rates across programme stages” were excluded due to conceptual redundancy and lower prioritisation.

In the **Comprehension and Knowledge Gain** domain, under *screening literacy*, “understanding benefits versus harms of screening” was retained as the more comprehensive literacy indicator, while “understanding screening purpose and eligibility” was excluded due to conceptual overlap. Within the *confidence and uncertainty* cluster, “reduction in ‘don’t know’ responses” was retained as a measurable indicator of improved certainty, whereas “self-rated confidence” was excluded, having received less than 40% importance.

For **Behavioural Change and Intention** domain, under *behavioural readiness*, “follow-through on recommended next steps” was retained as a concrete and measurable behavioural indicator, while the broader “movement along the readiness spectrum” was excluded due to its theoretical nature and greater difficulty in standardisation. In the *information behaviour* cluster, “shift toward evidence-based information sources” was retained as the most behaviourally meaningful indicator, whereas “use of decision aids or official tools” was excluded following its lower prioritisation (<40%).

Within **Health System and Empowerment KPIs**, under *confidence and agency*, “participation in shared decision-making” was retained as the strongest indicator of empowerment while “ability to prepare questions before appointments” was excluded as a supporting but less central indicator.

Finally, in the **Digital Literacy and Misinformation** domain, within the *source trust* cluster, “differential trust between professional, institutional, and peer sources” was retained as it captures calibrated trust rather than simple trust reduction, whereas “reduced trust in non-evidence-based sources” was excluded due to conceptual overlap. In the *information behaviour* cluster, “use of official or evidence-based digital resources” was retained as the most direct behavioural outcome, while “engagement with verified platforms” was excluded due to functional similarity.

Conclusions & Main Recommendations

This deliverable presents the development and validation of a structured, evidence-informed Key Performance Indicator (KPI) framework designed to monitor the impact, effectiveness, and equity of cancer literacy programmes across the CURTAIN consortium countries. Building on the systematic mapping of resources, stakeholders, and best practices (Tasks 2.1–2.3), and strengthened through a multi-country expert focus group and structured validation process, the proposed framework responds directly to identified evidence gaps in cancer literacy measurement.

The findings confirm a strong consensus that cancer literacy programmes must move beyond awareness-raising alone and demonstrate measurable impact across cognitive, behavioural, digital and system-navigation domains. Participants clearly prioritised comprehension and behavioural outcomes, particularly knowledge of early warning signs, understanding of modifiable risk factors, awareness of prevention and vaccination benefits and reduction of misconceptions. These indicators reflect the core expectation that cancer literacy initiatives should generate meaningful improvements in understanding that translates into action.

In addition, behavioural indicators such as actual screening uptake and vaccination initiation were considered the most defensible and policy-relevant outcomes of literacy programmes. This shows a shift toward accountability rather than solely attitudinal or self-reported outcomes.

Third, digital literacy and misinformation resilience is considered as a contemporary priority. The strongest endorsement across all domains was given to the ability to identify false or misleading claims, alongside confidence in challenging misinformation. This shows that cancer literacy now operates within a complex digital information ecosystem and must explicitly address disinformation risks.

Fourth, equity considerations were consistently integrated into prioritised KPIs. Indicators such as reach disaggregated by vulnerability and accessibility-adjusted outreach were strongly supported.

Fifth, the 40% importance cut-off proved effective in distinguishing core from optional KPIs, enabling the construction of a pragmatic yet comprehensive KPI set. The structured elimination of overlapping indicators improved conceptual clarity and reduced measurement burden without undermining domain coverage.

Main Recommendations:

Adopt a tiered KPI structure

Programmes should implement a two-tier model consisting of:

- Core KPIs (>40% importance) for mandatory reporting and cross-country comparability.
- Optional KPIs (<40% importance) for contextual adaptation and innovation.

This ensures both standardisation and flexibility across health systems.

Prioritise Outcome-Oriented measurement

Where feasible, programmes should prioritise behavioural and comprehension indicators (e.g., screening uptake, vaccination initiation, knowledge of warning signs) over purely process-based metrics (e.g., attendance rates).

Embed equity as a structural requirement

All outreach and outcome indicators should be disaggregated by relevant vulnerability dimensions (e.g., socioeconomic status, rurality, migrant background).

Integrate digital and misinformation resilience indicators

Given the high prioritisation of misinformation-related KPIs, cancer literacy programmes should systematically include indicators assessing the ability to detect false claims and challenge misinformation.

Use the KPI framework to inform policy and funding decisions

A validated KPIs set can provide a foundation for EU-level comparability and accountability. It can inform funding criteria, programme accreditation and future evaluation mechanisms within cancer control strategies.

Support capacity building for measurement Implementation

Training and technical guidance should accompany KPI adoption to ensure methodological consistency, particularly in measuring comprehension, misinformation resilience, and empowerment-related indicators.

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Appendix

Focus Group Discussion Guide

Developing a KPI Framework for Cancer Literacy Programmes

Moderation: Charis Girvalaki ENSP
Duration: 2 hours
Format: Moderated discussion + prioritisation
Outcome: A validated **menu of KPIs** aligned with evidence gaps and EU expectations

Opening & scope setting (10 minutes)

Short presentation of the systematic reviews main findings and task objectives

Alignment: What should cancer literacy programmes be held accountable for? (15 minutes)

Based on the evidence, what *types of change* should cancer literacy programmes reasonably be expected to deliver? Which of these are *non-negotiable*? Which are aspirational but still important?

- Awareness & understanding
- Trust & confidence
- Engagement with prevention or screening
- Ability to navigate the system
- Resistance to misinformation

Prioritising KPI domains (20 minutes)

How would you prioritise the following domains in a cancer literacy programme? Which domains must be included? Which do you consider core, important or optional?

- Reach and engagement
- Comprehension and knowledge gain
- Behavioural intention and change
- Health System & Empowerment KPIs
- Digital/health literacy skills
- Trust and misinformation resilience

For each option: Is this domain essential for accountability? Do we already over-measure this, or under-measure it?

KPI generation – Domain by domain (main section – 50 minutes)

A. Outreach KPIs – *Who is reached?*

What should programmes always report about *reach*? Which population breakdowns must be visible?

KPIs such as (POLL QUESTION):

- Proportion of target population reached
- Reach disaggregated by vulnerability (migrant status, rurality, gender)
- Use of trusted intermediaries (GPs, NGOs, community orgs)
- Proportion of **hard-to-reach populations** reached relative to their population share
- Geographic penetration (urban vs rural vs remote coverage index)
- Reach through **non-health settings** (schools, workplaces, religious/community centres)
- Percentage of outreach delivered in **non-dominant or minority languages**
- Accessibility-adjusted reach (materials adapted for low literacy, disability, or cultural relevance)

B. Engagement KPIs – *Who actively engages?*

What shows genuine engagement in literacy programmes?

KPIs such as (POLL QUESTION):

- Participation or attendance rates
- Completion of educational activities
- Repeat engagement or follow-up actions
- Interaction with healthcare professionals prompted by programme
- Average time spent engaging with programme materials or sessions
- Drop-off rates across programme stages (entry → completion)
- Participation in interactive elements (Q&A, quizzes, peer discussion)
- Engagement consistency over time (single vs sustained engagement)
- Self-reported perceived relevance of content
- Engagement among previously disengaged or sceptical participants

C. Comprehension & Knowledge gain KPIs – *What people understand*

What minimum understanding should programmes demonstrate improvement in?

KPIs such as (POLL QUESTION):

- Understanding of modifiable cancer risks
- Understanding screening purpose and eligibility
- Awareness of prevention and vaccination benefits
- Reduction in key misconceptions
- Ability to correctly interpret **personal cancer risk scenarios**
- Understanding of **benefits vs harms** of screening (overdiagnosis, false positives)
- Knowledge of early warning signs that require medical attention
- Ability to distinguish **prevention vs early detection** concepts
- Self-rated confidence in explaining cancer risks to others
- Reduction in “don’t know” responses to core cancer literacy questions

D. Behavioural change & intention KPIs – *What people do*

Which behaviours are most defensible as outcomes of literacy?

KPIs such as (POLL QUESTION):

- Intention to participate in prevention and screening programs
- Actual screening uptake (where applicable)
- Vaccination initiation
- Intention to seek support relevant with cancer risk factor (e.g. smoking cessation)
- Help-seeking when symptoms occur
- Shift toward evidence-based information sources
- Movement along the **behavioural readiness spectrum** (e.g. precontemplation - action)
- Follow-through on recommended next steps (booking appointments, requesting info)
- Sustained behaviour change at follow-up (where feasible)
- Reduced engagement in harmful behaviours (e.g. reduced tobacco use, quit attempts)
- Use of decision aids or official tools following participation

E. Health System & Empowerment KPIs – *How people interact with care*

What would indicate improved navigation or empowerment?

KPIs such as (POLL QUESTION):

- Confidence navigating cancer care pathways
- Understanding of treatment options and side effects
- Participation in shared decision-making
- Satisfaction with information received
- Confidence asking questions during medical consultations
- Awareness of patient rights and entitlements in cancer care
- Ability to prepare questions or information before appointments
- Reduced anxiety or uncertainty related to navigating cancer services
- Self-reported feeling of being taken seriously by healthcare providers
- Willingness to seek a second opinion when appropriate

F. Digital Literacy & Misinformation KPIs – *Critical in current context*

How do we know a programme improves resilience to disinformation?

KPIs such as (POLL QUESTION):

- Ability to identify false or misleading claims
- Reduced trust in non-evidence-based sources
- Increased trust in healthcare professionals
- Engagement with verified information platforms
- Recognition of emotional manipulation or conspiracy framing
- Reduced likelihood of sharing unverified cancer information
- Awareness of how algorithms influence health information exposure
- Use of official or evidence-based digital resources after intervention
- Confidence reporting or challenging misinformation
- Differential trust between professional, institutional, and peer sources

SMART CHECK (without measurement pressure) (15 minutes)

Group exercise. Are these KPIs, in principle:

- **Specific:** Linked to defined literacy outcomes
- **Measurable:** Quantitative/qualitative indicators with clear descriptors
- **Achievable:** Within existing national and project infrastructure
- **Relevant:** Directly addressing the gaps mapped in Tasks 2.1–2.3
- **Time-bound:** With predefined measurement intervals

Cross-Cutting KPIs

KPIs such as (POLL QUESTION):

- Equity impact score (gap reduction between vulnerable and general populations)
- Sustainability of outcomes (persistence over time)
- Participant-perceived usefulness for real-life decisions
- Scalability and transferability across settings or countries
- Burden of measurement vs value generated

Which KPIs are too vague to be useful?
Which need clearer wording?

Final prioritisation & consensus (10 minutes)