CLEAR·PC
Cancer Literacy Education and Awareness Resources for Prostate Care

D5.1 KEY INFORMANT INSIGHTS SUMMARY

WORK PACKAGE 5. EVALUATION OF HEALTH CONTEXTUAL DATA

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Abbreviations

CLEAR-PC	Cancer Literacy Education and Awareness Resources for Prostate Care
CSPA	Consejería de Salud del Principado de Asturias (Regional Ministry of Health in Asturias)
(d)HL	Digital and non-digital health literacy
dHL	Digital health literacy
D5.1	Deliverable Key informant insights summary
EC	European Commission
EU	European Union
FICYT	Fundación para el fomento en Asturias de la Investigación Científica y la Tecnología (Foundation for the promotion in Asturias of applied research and technology)
HL	Health Literacy
M-POHL	WHO Action Network on Measuring Population and Organisational Health Literacy
OECD	Economic Co-operation and Development
PCa	Prostate Cancer
SESPA	Servicio de Salud del Principado de Asturias (Health Service of Asturias)
WHO	World Health Organisation
WP	Work Package

EXECUTIVE SUMMARY

CLEAR-PC is a 36-month EU4Health project aimed at reducing inequalities in prostate cancer (PCa) outcomes by strengthening health literacy, digital health literacy, shared decision-making and patient engagement across Europe.

This Deliverable (D5.1) is framed in Work Package 5 (WP5) addressed to assess existing digital and non-digital health literacy ((d)HL) strategies, tools, and information, both related and unrelated to PCa.

The purpose of D5.1 is to provide a clear and comprehensive synthesis of:

- The key informants identified and engaged as relevant experts to provide information, tools, strategies and knowledge on (d)HL.
- The instruments used to collect information from the key informants identified.
- The analysis of the information about existing information, tools, and strategies related to (d)HL gathered from the key informant interviews and questionnaires conducted within the CLEAR-PC project.

The methodology followed for the development of D5.1 is based on strategic steps: 1) all CLEAR-PC partners worked on the identification of key health informants from their countries and abroad; 2) a work plan was defined which consisted of activities definition (general survey and in-depth interviews), materials development (scripts for the general survey and in-depth interviews and emails models to be used by the partners to reach out the key health informant identified); 3) an online tool for the delivery of the general survey was developed; 4) the general survey and the in-depth interviews were conducted; 5) qualitative analysis of the information collected; 6) reporting through D5.1.

The audience for D5.1 will be all potential stakeholders in the field of (d)HL and PCa, the general population and the European Commission.

The results obtained have been categorised in six main themes, which are: 1) Organisations, networks and participation; 2) Digital health literacy; 3) Quality and

comprehensibility of information; 4) Clinical communication and shared decisions; 5) PCa screening; and 6) Evaluation and research. In addition, five categories with the most mentioned ideas were identified for each theme, which are: 1) Tools and strategies; 2) Good practices and initiatives; 3) Gaps and challenges; 4) Recommendations; and 5) Links and repositories.

The main findings indicate that (d)HL initiatives are extensive but fragmented: while general HL information is widely available, there is a lack of specialised, culturally adapted, and easy-to-understand resources, especially for PCa. This gap limits both real understanding and decision-making.

Improving PCa health literacy requires shifting from generic information to an integrated, user-centred approach. Using surveys, in-depth interviews and a co-designed Stakeholder Matrix captured diverse perspectives with analytical rigor. Although many actors contribute, fragmentation, duplication and weak links between systems limit impact. General health information is abundant, but accessible, culturally adapted prostate-cancer resources are insufficient, reinforced by taboos and silence around men's health. Digital divides and reliance on "digital intermediaries" reduce autonomy, especially for older adults. Clinicians are trusted but often overestimate understanding, which points to the need for clearer materials and decision-support tools. Screening remains confusing due to inconsistent practice and lack of unified pathways, and gender patterns shape engagement, with women often acting as health navigators for men. Experts recommend co-creation with patients, emotionally engaging education formats, stronger digital tools, and evaluations that measure real-world behaviour, while addressing gaps such as palliative care and strengthening plain-language communication across the care pathway.

1. INTRODUCTION

1.1. Purpose of the deliverable

The purpose of the deliverable Key informant insights summary (D5.1) is to provide a clear and comprehensive synthesis of:

- The key informants identified as relevant experts who can provide information, tools and strategies and knowledge on health literacy and digital health literacy ((d)HL).
- The instruments used to collect information from the key informants identified.
- The analysis of the information about existing information, tools and strategies related to (d)HL gathered from the key informant interviews and questionnaires conducted within the CLEAR-PC project.

By consolidating the main themes, identified gaps, and strategic recommendations related to (d)HL in general and in PCa in particular, this report will serve as a fundamental reference to guide the project's subsequent activities.

D5.1 will serve as a basis for work package (WP) 5 leaders to complement the information gathered through the planned systematic database search, detailing identified (d)HL strategies, tools and information and initial analysis (Task 5.3). The analysis and synthesis of all the information will be carried out using a previously developed protocol (Task 5.4). In addition, a comparison of European and global sources will be carried out in a report and recommendations for improving (d)HL frameworks for PCa early diagnosis/screening, treatment decision making and palliative care in the European Union (EU) will be proposed (Task 5.5). The tools, strategies and best practices with higher standards in this analysis will be the potential ones to be included in the CLEAR-PC strategy.

This document will ensure that all partners share a common understanding of the perspectives, needs, and challenges expressed by experts and stakeholders. By highlighting converging viewpoints as well as critical areas requiring attention, the

summary report will support evidence-informed decision-making and contribute to the development of targeted interventions. Ultimately, these insights will help the consortium align its efforts, refine its strategic priorities, and work cohesively toward improving (d)HL for people affected by PCa, families and health professionals.

1.2. CLEAR-PC project overview

PCa is the most common cancer in men in Europe and one of the leading causes of cancer-related mortality. Despite major improvements in diagnosis and treatment, significant inequalities persist in:

- Access to screening,
- Patient knowledge and awareness,
- Digital health literacy,
- Shared decision-making between clinicians and patients,
- Care pathways across Member States,
- Quality of life outcomes for vulnerable groups.

CLEAR-PC addresses these challenges by co-creating, validating, and piloting resources that improve (d)HL, enhance shared decision-making, and empower patients and clinicians to navigate PCa prevention, diagnosis, treatment choices, and palliative care.

The project involves a multidisciplinary consortium of universities, healthcare providers, research institutions, patient organisations, public institutions, one professional organisation, and communication experts across Europe.

One of the specific objectives (SO2) of CLEAR-PC is to conduct a review of existing information, tools and strategies on (d)HL in the EU and globally related in both health and educational/formative contexts. The aim is to carry out a comprehensive review of existing information, tools and strategies related to (d)HL both in the EU and globally, focusing on their application in health (WP5) and educational (WP6) contexts. This review will assess the current state of knowledge, identify best practices and evaluate the effectiveness of different approaches used to improve (d)HL among various populations.

The results will inform the development or refinement of strategies to improve health education and training processes, ensuring that they are evidence-based, inclusive and adaptable to different health and education systems.

D5.1 falls under Task 5.1 – Identification of Key Health Informants, within WP 5 – Assessment of Existing (Digital) Health Literacy Strategies, Tools, and Information (related and non-related to PCa). The objective of Task 5.1 is to identify and engage (d)HL experts, specialised PCa healthcare providers, patient advocacy groups, policy makers, public health communication specialists, and psycho-oncologists to identify relevant initiatives, tools, strategies, and expert contributions that could support the development of the CLEAR-PC project.

1.3. Definitions

Key Health Informant

Individuals and organisations with (d)HL expertise, experience or leadership roles in PCa management. This includes, among others: (d)HL experts, specialised PCa healthcare providers, patient advocacy groups, policy makers, and public health communication specialists, and psyc- oncologists.

Key Informant Interviews

Key informant interviews comprise two types of actions within T5.1:

- General survey: questionnaire delivered to a wide range of experts to collect existing knowledge on successful initiatives, tools and strategies, gaps and challenges, and stakeholders related to (d)HL.

- In-depth interview: meeting with various experts who possess specialised knowledge on the same topics explored in the general survey, but approached in greater depth, allowing us to obtain insights and reflections that go far beyond what is possible through an online questionnaire.

2. METODOLOGY

This section describes the steps followed for the development of D5.1. The main activities carried out are:

- Identification and engagement of key health informants who have provided information on (d)HL and PCa to develop D5.1 and that will be engaged in CLEAR-PC to strategically contribute different activities during the project execution.
- Development and delivery of a general survey for the key health informants provide insights based on their expertise in the field of (d)HL and PCa.
- Conducting in-depth interviews with key health informants to get more detailed information rather than that obtained through the general survey.
- Analysis of the information collected from the key health informants.

2.1. Why stakeholders are important in CLEAR-PC project

Stakeholders are essential in a project like CLEAR-PC because they provide knowledge, perspectives and real-world anchoring that scientific research alone cannot generate. Their involvement ensures that the project remains relevant, feasible, ethically grounded, and aligned with the actual needs of the people and systems it aims to benefit.

First, stakeholders contribute context-specific expertise that researchers or project partners may not fully possess. In a European, multisite, and multidimensional initiative like CLEAR-PC, PCa care pathways, levels of HL, community structures, and health system organisation vary significantly across countries. Patients, caregivers, clinicians, health managers, policymakers, and community organisations all hold different kinds of situational knowledge that help the project understand how interventions will operate in practice, which barriers may arise and which adaptations are needed to make the outputs meaningful for each setting.

Second, stakeholders ensure that the project addresses genuine needs rather than assumptions. In the field of PCa and HL, lived experience is a key source of insight. Patients and caregivers can articulate gaps in communication, emotional demands, or navigation challenges that are often invisible in clinical or academic discourse. Similarly, healthcare professionals or patient organisations can identify systemic obstacles or resource constraints

that must be considered to design realistic and scalable interventions. Without this input, there is a risk of developing solutions that are theoretically sound but unimplementable or misaligned with user priorities.

Third, involving stakeholders enhances the co-creation process, which is central to the CLEAR-PC approach. Co-creation strengthens the quality and legitimacy of project outputs, because solutions are built with—not only for—the people who will ultimately use them. This increases acceptance, reduces resistance to change, and enhances the sustainability of interventions. Moreover, stakeholders help refine the focus of work packages, highlight overlooked dimensions of HL, and contribute to the design, testing and evaluation of tools or strategies.

Fourth, stakeholders are essential for ethical robustness and transparency. Engaging them openly and systematically demonstrates accountability and ensures that sensitive issues—such as communication about PCa, decision-making processes, consent, stigma, or inequalities in access to information—are approached with respect and cultural sensitivity. Their contribution helps ensure that the project complies with ethical norms, respects patient autonomy and incorporates diverse perspectives, including those that are traditionally underrepresented in research.

Finally, stakeholders are instrumental for dissemination, policy translation and long-term impact. Policymakers, health system representatives and patient organisations can transform project results into actionable recommendations, integrate them into national strategies or reshape clinical pathways. Their involvement from the beginning fosters ownership and increases the likelihood that CLEAR-PC outputs will be adopted beyond the project's duration.

In summary, stakeholders are not merely external collaborators; they are co-producers of knowledge and key drivers of relevance, feasibility, impact and sustainability. Their contributions strengthen the scientific quality of CLEAR-PC while ensuring that the project remains grounded in real-world needs and capable of generating meaningful improvements for people living with PCa across Europe.

2.2. Mapping what matters: A co-designed framework for building the CLEAR-PC stakeholder matrix

Given the importance of stakeholders in the project, establishing a Stakeholder Matrix was crucial. The leaders of all CLEAR-PC WPs collaborated on the development of the Matrix, following a structured, evidence-based qualitative methodology. This methodology aimed to ensure consistency, transparency, and usability across all WPs throughout the project's duration.

The process began, conducted by the leaders of task T5.1, with a specific review of conceptual frameworks and empirical studies on stakeholder engagement in health research, PCa, and HL. This review laid down the theoretical groundwork for defining relevant stakeholder categories, clarifying their potential roles and modes of participation, and identifying the key variables that would guide their involvement in project activities.

Based on this initial synthesis, a preliminary version of the Stakeholder Matrix was developed and distributed to the WP leaders before a focus group meeting, which took place on November 10, 2025. This distribution was accompanied by a set of questions (see Annex 1 - Focus group for the development of a Stakeholders Matrix), designed to encourage reflection on the usefulness of the different parts of the matrix and the appropriateness of including or removing various elements. This initial distribution aimed to familiarise all partners with the proposed structure and allow them to prepare constructive feedback in advance.

During the subsequent focus group, which brought together the leaders of all CLEAR-PC WPs, each component of the proposed matrix was examined in detail. Participants collaboratively discussed which elements should be added, removed, or refined, always with the goal of ensuring the matrix was functional and relevant to all WPs and remained useful throughout the project lifecycle. This session followed a co-design approach and enabled WP leaders to operationalise the conceptual categories by defining stakeholder types, specific roles within the project, areas of expertise, linkages to WP tasks, and ethical considerations related to consent, data sharing, and regulatory compliance.

WP8 leader was unable to participate in the focus group meeting due to scheduling issues, but their contribution was provided in writing and added to the contributions made by the rest of the consortium.

The results of this collaborative process were subsequently translated into a standardised data matrix, which was then further checked and verified by the WP leaders to ensure internal consistency, eliminate overlapping categories, improve clarity, and align the matrix with CLEAR-PC's scientific and operational objectives, including stakeholder involvement in needs assessment, co-creation of interventions, pilot testing, dissemination, and policy implementation.

2.3. Stakeholder matrix: The final version

The final version of Stakeholder Matrix (see Table 1) includes different items that are interconnected:

Table 1. CLEAR-PC Stakeholders Matrix

Themes	Specific information	Categories
General information	Partner in charge	Partner acronym
	Stakeholder name	Name
	Stakeholder organisation	Organisation name
	Stakeholder country	Country name
	Stakeholder category	Healthcare professional Policy maker Academia Education Group of patients in the different states (Associations, companies…) Patient Advocacy group Caregiver Expert in HL Professional medical association (International and national) ONG Media journalist organisation Influencer EU funded project Expert Champion International health organisation National health organisation
	Stakeholder role	Advisor

		Reviewer Recruiter Key Informant Just receive information about the project
	Stakeholder area of expertise	PCa Urology Primary Care HL Educational resources Cocreation Policy Engagement Shared decision making Patient care Palliative care Education informants Self-management Support to Ukrainian migrants Health communication Communication expert on cancer Digital education Misinformation Digital
	Level of influence of the stakeholder	European National Regional Local
Task where stakeholders can be involved	Description of the tasks and the months in which the different tasks of the project are developed	According to GA
Stakeholder contacts (to fill in after having reached out to the stakeholder)	Partner who contacted the stakeholder	Yes/No
	Partner who contacted the stakeholder	Partner acronym
	Does the stakeholder prefer the communication in English, or they can only participate in activities in their own language? Indicate Yes if in English	Yes/No
	Did the stakeholder approved sharing their contact details with project partners and the European Commission for reporting purposes?	Yes No They approved to be contacted only by the partner in charge
	If yes, please add here their email	Mail
	Has the stakeholder appointed a substitute?	Yes/No
	If yes, indicate name of the substitute	Name

	If yes, indicate Email of the substitute	Mail
	Did the stakeholder confirm their collaboration in CLEAR-PC?	Yes No Pending confirmation
	Compensation requested?	Yes No
	Additional information (open field)	Additional information Partner who added the information

By clearly linking each stakeholder group to specific project activities, the matrix facilitates systematic engagement monitoring, coordination across WPs, and addresses well-known methodological challenges in stakeholder research, such as inconsistent reporting, limited transparency, and insufficient integration of stakeholder contributions into decision-making processes.

Overall, the CLEAR-PC Stakeholder Matrix is a robust theoretical and practical tool that strengthens the quality, relevance, and scalability of stakeholder engagement in the project. By combining evidence from the literature with participatory co-design and structured operationalisation, the procedure enhances methodological rigor while ensuring that stakeholder engagement remains meaningful, consistent, and aligned with CLEAR-PC's overall objectives.

2.4. General survey and in-depth interviews

Within WP5, Task 5.1 focuses on identifying and engaging key health informants with expertise in digital and non-digital health literacy (d)HL and prostate cancer (PCa). This task aims to build a robust expert base capable of informing a contextual review of existing strategies, tools, and information throughout the entire PCa care pathway. To achieve this, the CLEAR-PC team designed two complementary instruments that helped capture the HL needs and perspectives at all stages of PCa, from screening and diagnosis to treatment, survivorship, and palliative care, and from all relevant stakeholder groups, including healthcare professionals, caregivers and families, and individuals diagnosed with PCa.

The first instrument, called the general survey, gathered essential information on participants' opinions and experiences regarding (d)HL in general and PCa in particular.

It included key elements that addressed the different stages of the primary cancer care process, perceived barriers and facilitating factors for accessing and understanding health information, and the types of support needed to improve communication and patient guidance. The general survey also invited participants to indicate their willingness to complete a comprehensive in-depth interview and offers them the option of joining the project as stakeholders, thus contributing to future phases of CLEAR-PC. This instrument was designed to be concise, accessible, and suitable for a wide range of participants, ensuring high participation and representativeness.

It was self-administered, with information collected via a Forms-Teams link and an invitation email model was developed for consistency among all the CLEAR-PC partners when inviting the key health informants identified. Both the Forms survey and the invitation email were translated into the four languages used by the CLEARPC partners.

Participants who expressed interest and availability were subsequently invited to participate in an in-depth interview, which explores the most relevant themes identified during the brief survey in greater detail. This second instrument was aimed at key informants who could provide more comprehensive qualitative information on the challenges and opportunities of HL in their local contexts. The comprehensive survey was administered via online interviews conducted by the research team. Prior to the interviews, participants were sent an information sheet to obtain their verbal consent to participate once the interview recording began. Seven in-depth interviews were conducted from October 2025 to March 2026. These interviews were conducted on Microsoft Teams, recorded with the participants' consent, and automatically transcribed using the platform's transcription tool to ensure accuracy and facilitate subsequent qualitative analysis. During the interview, a summary of the CLEAR-PC project and the aim of the interview were presented. Then, six questions were introduced to get knowledge on different aspects: the expertise of the stakeholder experience related to HL, (d)HL, or PCa care; existing tools, initiatives, or strategies (at local, regional, or international level) to support HL or (d)HL in cancer, especially PCa, when applicable, for the general population, patients, healthcare professionals, and policymakers; good practices or successful models (locally, nationally or globally) that could inspire or be adapted for PCa

prevention, diagnosis, treatment, or palliative care; gaps, barriers, or unmet needs in the field of health literacy for cancer patients, particularly vulnerable groups and men over 40; types of stakeholders (professionals, organizations, patient groups, and the general population) should play a key role in improving HL among PCa patients and their families; and, actions, improvements, or research priorities the stakeholder may consider essential for strengthening (d)HL in the coming years.

Together, the general survey and the in-depth interviews provide complementary levels of information that reinforce the analytical rigor of WP5. The general survey ensures broad coverage of the population involved in primary cancer care, while the in-depth interviews capture expert and contextualised perspectives, essential for understanding variations in HL practices, information needs, and systemic limitations across different European settings. Both instruments, which can be consulted in the annexes, represent fundamental components of Task 5.1 and contribute directly to the identification of key health informants who will support the development, implementation and evaluation of CLEAR-PC interventions.

The answers gathered through the general survey and the in-depth interviews were analysed and structured into six themes and five categories.

3. RESULTS

The results described in D5.1 are structured in three different categories:

- Description of the stakeholders identified and engaged in WP5,
- Analysis of the information collected from the general survey,
- Analysis of the information collected through in-depth interviews.

3.1. Description of the stakeholders identified and engaged in WP5

A great number of stakeholders from different countries have been identified by all CLEAR-PC partners at a first stage: 462 stakeholders from 42 different countries. Different profiles of expertise were included in the selection process:

- (d)HL experts, such as academic researchers focusing on (d)HL (related and non-related to PCa) (potential informants: researchers from the European HL Project (HLS-EU). We will also include digital health tool developers involved in the development of eHealth or mHealth tools for cancer patients.
- Specialised healthcare providers, such as psycho-oncologists/urologists/primary care clinicians, who provide direct patient care, and nurse practitioners.
- Patient advocacy and support groups, such as experts from Europa Uomo, which allow to get in contact with PCa survivors and expert patients, who have become advocates or peer educators.
- Associations and societies, such as the European Association of Urology and the European Society of General Practice/Family Medicine (WONCA Europe).
- Policy makers and public health officials, such as national and regional experts from national and regional health administrations.

- Public health communication specialists focused on cancer awareness, prevention, patient education, and citizen engagement.

Tables 1 and 2 below show the distribution of stakeholders per country in 42 European Union (EU) and non-EU countries.

Figure 1 shows the stakeholders identified in 25 countries in the EU.

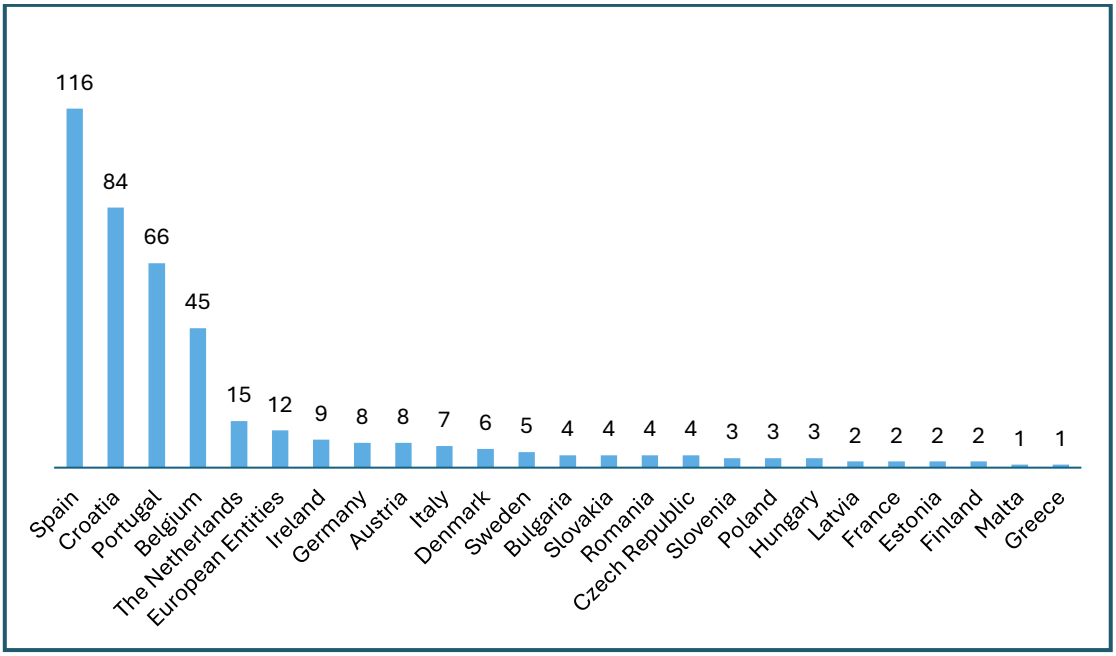

Figure 1. Stakeholders identified in EU countries

Figure 2 shows the stakeholders identified in 17 countries in the countries out of EU.

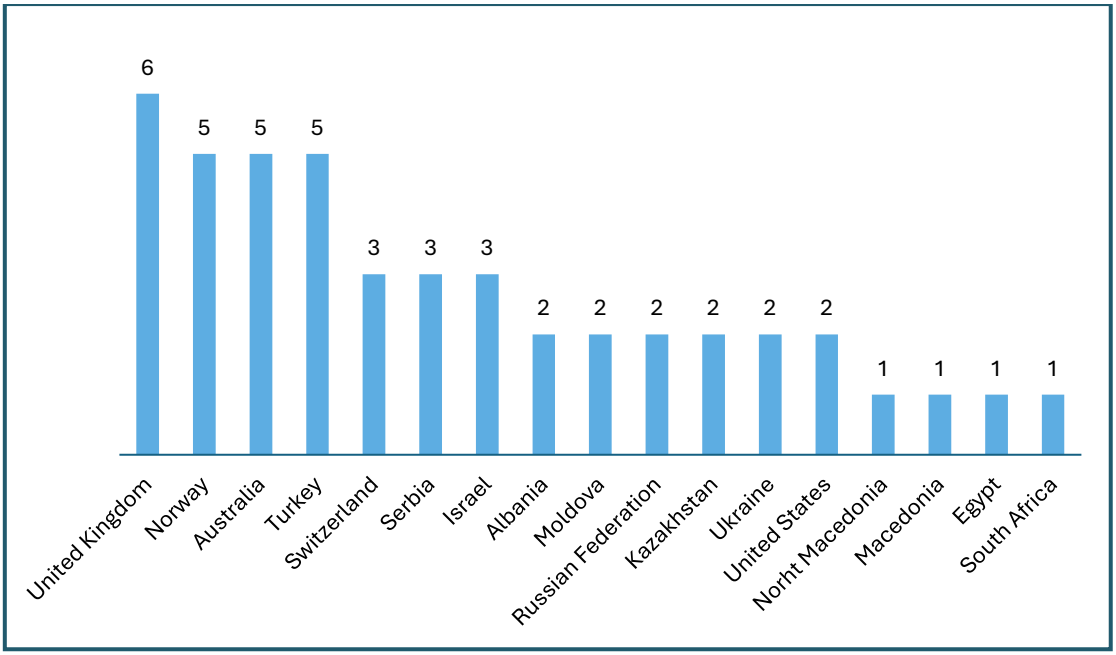

Figure 2. Stakeholders identified in non-EU countries

All stakeholders were included in a registry created by CLEAR-PC specifically for this purpose. Once stakeholders were identified and registered, a series of emails were sent to all listed contacts. The invitations were distributed using different approaches: (1) a formal invitation email with a template requesting completion of the survey on tools and strategies; (2) individual outreach to stakeholders previously known from earlier collaborations; and (3) phone calls to the closest stakeholders.

We received 111 valid responses to the survey collected between 23 December 2025 and 4 March 2026 from different profiles of expertise and different countries.

Stakeholders were invited to complete the survey, and one of the questions encouraged them to continue participating in future CLEAR-PC activities. As a result, 52 stakeholders expressed interest in being contacted for additional CLEAR-PC activities, and 58 will just be informed about the activities and results of the project (figure 3).

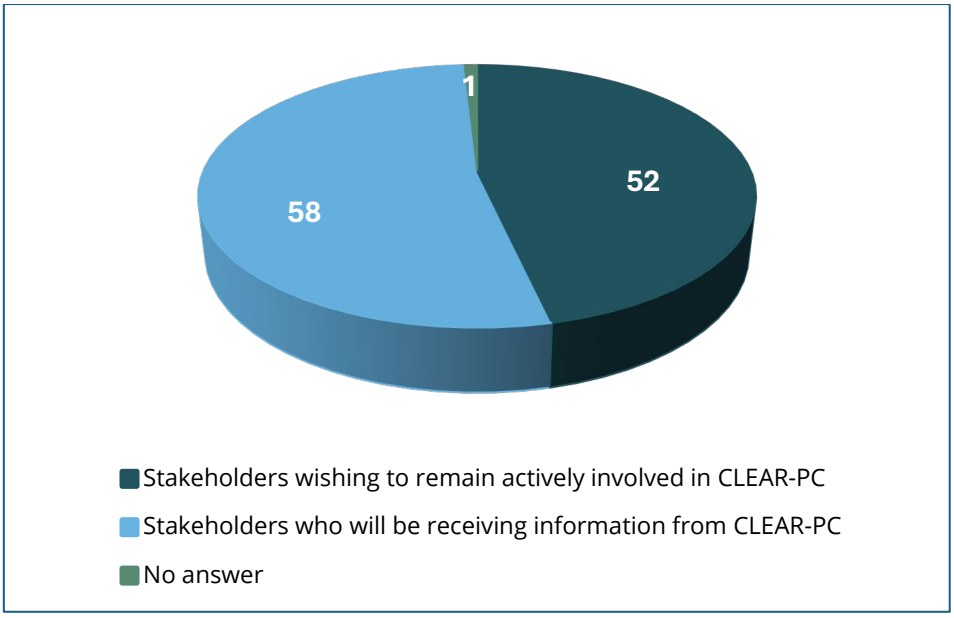

Figure 3. Number of stakeholders involved in CLEAR-PC

The questionnaire was answered in the language chosen by the respondent. Finally, it was completed in five languages, as shown in table 2. This ensures that the results obtained are representative of the entire CLEAR-PC consortium.

Table 2. Responses received by language

Language	Number of responses
Spanish	53
Portuguese	19
Croatian	13
Dutch	8
English	18

Different types of organisations gave feedback on the survey:

- Public health administrations and health care organisations: National and regional ministries of health.
- Universities and research organisations, including in this category public and private universities and research organisations.
- Civil society and professional organisations, such as NGOs, associations, foundations, federations and patient associations.

- Healthcare entities: Public and private hospitals and primary care centers.
- Private entities, including in this category entities ruled under private regulation offering services in the fields of health care, social services, health equity, social and digital innovation, inclusive solutions, well-being, active citizenship and quality of life.

The analysis of the type of organisation shows a variety of backgrounds among the respondents (figure 4), which is key to CLEAR-PC objectives: Public administrations and health care organisations (32.73%) are key players in governance, policy institutionalisation, health care and resource management; Universities and research centres (30%) are responsible for evidence-based reasoning and methodological rigour; Civil society organisations and NGOs (23.64%) are entities that show the most realistic situation of patients and their families, and the professional associations of the professionals they represent; Finally, the private sector and other profiles (13.63%) include the complementary perspective of the technology and pharmaceutical industries as vectors of innovation.

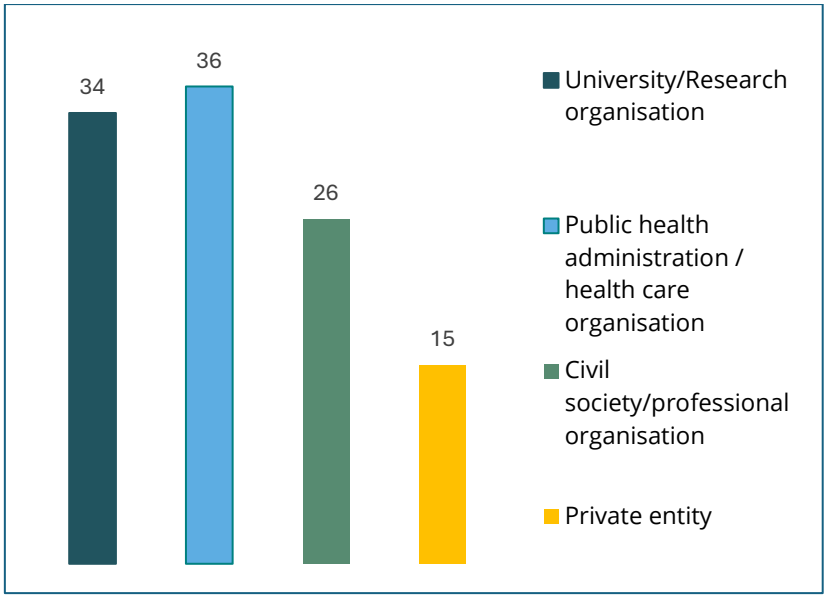

Figure 4. Responses received by type of entity

3.2. Analysis of the information collected from the general survey

This report presents the main insights obtained from the general survey delivered to the key informant experts identified in different fields of (d)HL and PCa. Given the qualitative

nature of the information collected and the large number of responses, the report organises and groups the information thematically after a structured coding process. It also incorporates anonymised quotes (KI-XXX) and relevant links provided by respondents. Five categories were identified (table 3).

Table 3. Categories after first qualitative analysis

Indicator	Number
Key informants (n)	111
Responses analysed (n)	707
Categories per informant	Tools and strategies Good practices and initiatives Gaps and challenges Recommendations Links and repositories

Through subsequent thematic coding, the 707 responses were organised into 6 main themes, revealing the most frequently mentioned ideas (table 4):

Table 4. Numbers and percentage of mentions for each main theme

Themes	Mentions (n)	%
Organisations, Networks and Participation	166	39,43%
Digital health literacy	171	34.40%
Quality and comprehension of information	92	18,51%
Clinical communication and shared decisions	36	7.24%
Prostate cancer screening	17	3.42%
Evaluation and research	15	3,01%

The analysis of the question "*Type of stakeholder suggested*" was analysed separately from the previous thematic analysis. Table 5 below shows the stakeholders suggested by the key health informants as most relevant in response to the question *"Which types of population profiles should participate more actively in improving HL on PCa?"*:

Table 5. Profiles of stakeholders suggested by key health informants

Profile	Mentions (n)
Health care professionals	103
Patients / families (caregivers)	90
General population	74
Public health administration	4

Results of the general survey show that (d)HL is a cross-cutting responsibility. CLEAR-PC data indicates that the active involvement of healthcare professionals (38%), families (33%), and the general population (27%) is required. It is also considered important to integrate educators and informal community leaders to amplify the impact.

Sections 3.2.1 to 3.2.6 below provide a description of the analysis carried out by theme and category.

3.2.1. Organisations, networks and participation

The analysis of the theme on Organisations, Networks and Participation reveals a highly heterogeneous landscape in which international and national institutional bodies, third-sector organisations, community platforms, professional networks, and private-sector entities of diverse origins and purposes converge. All of them are involved in HL initiatives. A total of 166 coded mentions were identified across the questionnaire categories (tools and strategies, good practices and initiatives, gaps and challenges, recommendations, and relevant links) indicating both the relevance and the necessity of this thematic area.

As interpreted from the general survey, organisations and associations operate as amplifiers, mediators and translators between scientific evidence and the general public. These range from global agencies, such as the World Health Organisation (WHO) or the Organisation for Economic Co-operation and Development (OECD), to national Ministries of Health, local networks, patient associations, and community-based platforms. All of them play a key role in generating resources, designing campaigns, producing educational materials, enabling participatory processes, and shaping support strategies within HL. Likewise, the presence of multiple European and national initiatives demonstrates a strong effort to align policies with the European Cancer Plan and emerging HL frameworks.

However, qualitative analysis of the gaps and challenges reveals persistent structural problems: fragmentation, duplication of efforts, lack of coherence across administrative levels, weak connections between schools, communities and the health system, social and demographic inequalities, and the need to integrate HL throughout the entire life

and care continuum. The collected recommendations consistently point to the need to institutionalise HL as a cross-cutting axis, strengthen citizen participation in intervention design, and ensure sustained, equitable and geographically adapted strategies.

Key aspects:

Solid governance framework for health literacy

A solid international and national governance framework currently provides coherence and strategic validation for (d)HL. This framework is articulated around three major pillars:

1. **Normative Bodies (WHO and OECD):** These institutions act as guarantors of quality and cost-effectiveness. While the WHO monitors the global impact of HL through international observatories, the OECD establishes standards for person-centred care aimed at reducing inefficiencies.

2. **European Operational Framework (M-POHL and European Commission):** The WHO Action Network on Measuring Population and Organizational Health Literacy (M-POHL) provides the technical infrastructure needed to measure organisational HL, enabling Member States to make informed policy decisions. Meanwhile, the European Commission supports and finances cancer research as part of its strategic priorities.

3. **Innovation Networks (Cancer Mission):** Through the Cancer Mission Clusters, Horizon Europe promotes collaborative structures connecting researchers, policymakers, healthcare providers and civil society. These clusters aim to coordinate research, innovation and policy actions in priority areas such as prevention, early detection, diagnosis, treatment and survivorship.

Fragmentation of strategies within organisations

The analysis of the 166 coded mentions extracted from tools, best practices, gaps, and recommendations reflects an area for improvement. It also proposes recommendations to address it.

Patient associations are recognised as key actors throughout the HL process. Respondents advocate for structured co-creation protocols, ensuring that organisations such as the Spanish Association Against Cancer (AECC), participate from the earliest stages of the interventions and campaign design.

Primary Health Care is also highlighted as the foundation of the system, for rolling out HL programmes tailored to the characteristics of each territory and segmented according to care needs (simple or complex), with the collaboration of health professional associations through the participation of professionals, both retired and active, committed to their community.

Table 6 shows a summary of the key health informants' contributions for the theme Organisations, Networks and Participation. Verbatim quotes were taken from the transcripts and can be seen in Annex 6 (Verbatim quotes - Organisations, Networks and Participation).

Table 6. Content of theme Organisations, Networks and Participation

Categories	Theme: Organisations, Networks and Participation
Tools / Strategies	**NATIONAL, INTERNATIONAL, AND EUROPEAN GOVERNMENTAL ORGANISATIONS** OMS: Global cancer observatory - https://gco.iarc.fr/en Ministries of Health of Member States M-POHL - https://m-pohl.net/ OCDE - https://www.oecd.org/en.html
	THIRD-SECTOR ORGANISATIONS ANCAP: Spanish Prostate Cancer Association VSFM: Association for the Promotion of Self-Management AECC: Spanish Association Against Cancer GEPAC: Spanish Cancer Patient Group Portuguese League Against Cancer - https://www.ligacontracancro.pt/educacaoi SPLS: Portuguese Society for Health Literacy PHAROS: Dutch national centre of expertise on health disparities Neetherlands - https://www.pharos.nl/over-pharos/ The League Against Cancer in Čakovec County (Međimurje), Croatia, includes the Prostate Cancer Club Colombian League Against Cancer Portuguese Association of Prostate Cancer Patients - https://www.apdprostata.com/ Movember (international) - https://es.movember.com/ ÖPGK: Austrian Platform for Health Literacy - https://oepgk.at/

Categories	Theme: Organisations, Networks and Participation
	OTHER ENTITIES OR ORGANISATIONS SMRC: Management Resource Center **-** https://selfmanagementresource.com/ Spanish Health Literacy Network - https://www.alfabetizacionsalud.com/ German Network on Health Literacy - www.dngk.de
	HEALTH LITERACY NETWORK Networks from the Ministry of Health of Spain such as the Network of Health Schools for Citizenship - https://www.redescuelassalud.es/
Good Practices / Initiatives	**WHO**: The European Code Against Cancer, 5th edition (ECAC5) consists of 14 recommendations based on current scientific evidence on personal behavioural factors, environmental factors, and medical interventions, specific to the general population in the EU - https://cancer-code-europe.iarc.who.int/ **European Comission**: Funding and support for European cancer projects. EC gives place to 10 flagship initiatives and 32 support actions. EU4HEALTH - https://health.ec.europa.eu/non-communicable-diseases/cancer/europes-beating-cancer-plan-eu4health-financed-projects_en **European Comission**: European Cancer Plan https://commission.europa.eu/topics/public-health/european-health-union/cancer-plan-europe_es **EU Cancer Mission**, Horizon Europe: Cancer Mission Clusters, which bring together policymakers, healthcare professionals, researchers, patient organisations and civil society actors from across Europe. These working groups aim to coordinate research, innovation and policy actions in key areas such as cancer prevention, early detection, diagnosis, treatment and quality of life for cancer patients and survivors - https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/eu-missions-horizon-europe/eu-mission-cancer/implementation-page_en **M-POHL**: Improves the responsiveness of healthcare organisations in terms of HL by facilitating the assessment of organisational HL in healthcare organisations. Promotes programmes that involve the participation of citizens and professionals, such as OPHELIA - https://m-pohl.net/node/104 **OCDE**: It acts as a global forum for comparing experiences, seeking solutions to common problems and establishing international standards. It conducts cost-effectiveness studies - https://www.oecd.org/en/publications/health-literacy-for-people-centred-care_d8494d3a-en.html
	MINISTRIES OF HEALTH **CROATIA** The Ministry of Health provides the legislative framework. At the local level, such as Međimurje County, there is also no specific strategy, but in the Međimurje County Development Plan until 2027 there is a section related to health (https://medjimurska-zupanija.hr/strateski-dokumenti/) and which also includes HL, there is also one document that is no longer current, the Strategic

Categories	Theme: Organisations, Networks and Participation
	Plan for Improving Health and Reducing Health Inequalities in Međimurje County from 2014-2020. The Strategic Plan for Tackling Health Inequalities in Međimurje County through Health Promotion 2014-2020 (First strategic plan to reduce health inequalities). https://zzjzck.hr/upload/publikacije/Strate%C5%A1ki%20plan%20za%20unapre%C4%91enje%20zdravlja%20i%20smanjivanje%20nejednakosti%20u%20zdravlju%20u%20Me%C4%91imurskoj%20%C5%BEupaniji%20od%202014.-2020.pdf **Zdravko:** National digital platform and digital assistant and gynaecologist and cervical cancer from the Croatian Institute of Public Health, national program for early detection of cancer, breast, colorectal, lung and cervical cancer. European plan to defeat cancer. https://www.vpz.hr/2021/11/virovitici-odrzana-javnozdravstvena-akcija-mjesec-borbe-raka-naglasak-stavljen-prevenciju-rano-otkrivanje/ https://www.zzjzvpz.hr/index.php?sadrzaj=djelatnost&dj=3&djtxt=novostijavvise&novtxt=657 **Necurak-:** The National Cervical Cancer Screening Programme covers all women in Croatia aged between 25 and 64 - https://necurak.hzjz.hr **GERMANY** Cancer Information Service - https://www.krebsinformationsdienst.de/ at the German Center of Cancer Research - https://www.gba.de/service/versicherteninformationen/frueherkennungsuntersuchungen/ German Center of Cancer Research and the website of the German Cancer Aid https://www.krebshilfe.de/informieren/ueber-krebs/ **PORTUGAL** HL is supported by national policy through the National Health Literacy Action Plan led by the Direção-Geral da Saúde, National Cancer Hub Portuguese strategy to fight cancer: “"Treating Cancer Yourself" (https://tratarocancroportu.pt/). **SPAIN** **Estrategia en Cáncer del Sistema Nacional de Salud 2021** https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/cancer/docs/ESTRATEGIA_EN_CANCER_DEL_SNS.pdf **PyDeSalud:** Spanish Ministry of Health. Website to promote citizen participation in decisions about their health - https://pydesalud.com/recursos-sobre-la-alfabetizacion-digital-sanitaria/ **Network of Health Schools for Citizenship Spain. Examples:** Osasun Eskola - https://osasuneskola.osakidetza.eus/es/home: provides information and training in a more interactive way to promote intuitive and dynamic learning.

Categories	Theme: Organisations, Networks and Participation
	Andalusian School for Patients - https://www.easp.es/project/escuela-de-pacientes-2/: training for chronic patients and their families to improve their self-care and self-management of their illnesses. **Regional strategies involving the third sector**: Government of the Canary Islands: Healthy Canary Islands https://www3.gobiernodecanarias.org/canariasaludable/
Gaps / Challenges	It is proposed that HL should begin at school age in order to promote a sustained sociological shift towards greater personal responsibility for one's own health. and, from a realistic perspective, it is proposed to take advantage of the Primary Care network in Asturias to roll out a HL programme adapted to the characteristics of each territory and segmented according to care needs (simple or complex), also counting on the collaboration of the health professional associations through the participation of professionals, both retired and active, committed to their community.
	A growing challenge is identified in relation to population ageing, with the consequent increase in comorbidities and long-term survivors, for whom it is a priority to establish clear follow-up protocols and well-defined channels of access to the social and healthcare system, also incorporating a support and accompaniment network that addresses unwanted loneliness and guarantees continuous care for these patients.
	Weak connection between schools, communities and health systems.
Recommendations	Convey information about the most common types of cancer to the population in a more specific and direct manner.
	Integrate HL throughout the entire care pathway (prevention/screening, diagnosis, treatment decisions, survival and palliative care), not just in campaigns.
	Training for the general public, informal carers, as well as formal training on communication with patients and their families.
	Involve the target population to better understand their needs and engage them in the participation and design of these interventions.
Resources and links	https://www.escueladepacientes.es/cancer/cancermama/guias-cancer-de-mama https://www.escueladepacientes.es/cancer/cancer-colorrectal/guias-cancer-colorrectal

Categories	Theme: Organisations, Networks and Participation
	https://www.saludcastillayleon.es/escueladepacientes/es/enfermedades/cancer https://canalsalut.gencat.cat/ca/salut-a-z/c/cancer/tipus/ https://www.escuelacantabradesalud.es/web/escuela-cantabra-de-salud/cancer-de-mama https://www.comunidad.madrid/servicios/salud/cancer https://www.osakidetza.euskadi.eus/enfermedades-cancer/webosk00-oskcon/es/ https://einasalut.caib.es/web/paciente-activo/cuidate-con-tu-enfermedad https://www.icv.hr/icv-radio/pricamo-o-zdravlju-benes-karcinomi-su-preventivni-i-ljudi-ih-ne-moraju-imati-samo-je-bitno-da-se-vise-vremena-posveti-vlastitom-zdravlju/ https://magazin.hrt.hr/sretni-i-zdravi/strucnjaci-apeliraju-briga-za-zdravlje-krece-od-svakog-pojedinca-10893520 https://www.radioslatina.hr/prevencijom-do-zdravlja/ https://nismosame.com/izvjestaj-o-radu/izvjestaj-o-radu-nismo-same-u-2023-godini-prvi-dio/ https://es-es.fastheroes.com/ https://www.sanidad.gob.es/areas/promocionPrevencion/home.htm

3.2.2. Digital health literacy

The analysis of the (d)HL dimension is just as thorough as the one described above. The variety and breadth of the contributions made by the key informants are grouped into the same themes already described, through the analysis of 171 codes.

Numerous European projects, digital platforms, professional networks, patient associations, and national and international strategies working on HL from complementary perspectives are identified: education, communication, participation, patient support, shared decision-making, and combating misinformation.

The tools and strategies range from structured EU projects (IDEAHL, CAREWAY, CURTAIN, INTERVENE, HELEM-EU) to national platforms (PyDeSalud, GuíaSalud, SNS Digital Health Strategy) and methodologies such as OPHELIA, Teach-Back or the systematic use of apps, social networks, POC channels and HL assessment scales. Generic HL strategies are described, some more specific to cancer, and the section concludes with those specific to prostate cancer.

Good practices range from established programmes (Health Schools Network, Osasun Eskola, Andalusian School for Patients, Austria Health Literacy Alliance) to community experiences, inclusive materials, clinical guidelines, communication initiatives, creative campaigns (AECC, Movember, Let's Talk About the Prostate) and peer support projects.

With regard to the gaps and challenges identified, these include the persistence of disease-centred approaches, the lack of tailored messages, the negative impact of misinformation, the influence of social media, poor understanding of complex medical information, social inequalities and digital divides, as well as insufficient shared decision-making and a lack of clear information to break down taboos.

The recommendations aim to institutionalise HL as a cross-cutting priority (health, education, social services), invest in research, ensure accessibility and clear language, involve citizens, strengthen high-quality digital tools, create European observatories, prioritise organised screening, promote health education in schools and improve communication policies.

Key aspects:

European frameworks providing the theoretical and technical basis

As in the organisational dimension described above, digital literacy in health is based on a broad and robust scientific and technical framework: The IDEAHL project offers the methodology for digital empowerment; CAREWAY acts as the reference model for Linguistic Accessibility through the co-design of multilingual educational resources; and CURTAIN establishes the roadmap for training 'Cancer Literacy Ambassadors,' a key figure in reducing structural inequalities. Together, these frameworks transform HL from an abstract concept into an executable local strategy focused on three cardinal objectives: prioritising literacy as a political and health priority, implementing multilingual resources and plain language to remove barriers in underserved populations and improve accessibility, and facilitating quality digital tools and personalised risk understanding.

Challenges for prostate cancer

Although there are many resources for HL in general, and some are more cancer-specific, there are far fewer initiatives specifically for prostate cancer.

These initiatives address organised early detection programmes, following models such as the PETER project in Slovenia. Others guarantee mass access to risk assessment tools such as the Risk Checker, which allows citizens to understand their vulnerability in seconds, facilitating 'prevention literacy' that demystifies the PSA test and its implications.

It is also interesting to note that successful initiatives related to prostate cancer not only contribute to increasing knowledge, but also to correcting rumours and taboos, such as the MitoHomes – ProstataHOme initiative.

Cancer as a life process

In this regard, tools such as Point of Care (POC) channels are being developed to provide educational information at the time of consultation. The adoption of validated Option Grids (interactive decision grids) allows patients to compare treatment options based on their personal values and test results, transforming uncertainty into an informed choice.

And, tentatively, the importance of peer support and the evolution or transition to palliative care is mentioned. Peer support should be formalised through programmes such as 'Cancer Thriving and Surviving'. In palliative phases, it is essential to implement inclusive materials that explain symptom management and expectations in a simple way, using digital tools such as Symptom Navi for close cooperation between patients and specialists throughout the entire care chain.

Some good practices and methodologies

Although there are many tools, strategies, good practices and methodologies in use (see Table 6 and Annex 7 - Verbatim quotes - Digital Health Literacy), we highlight here those that directly or indirectly involve the end-user:

1. **OPHELIA Methodology**: Used for authentic community consultation and collaboration, ensuring that cancer interventions respond to real local needs and not clinical assumptions.

2. **Teach-Back Technique**: Established as the gold standard in cancer consultation to verify patient understanding by asking them to explain the treatment plan in their own words.
3. Critical and Specific Digital Literacy:
    - **LeesSimpel App**: A tool designed specifically for people with low HL, simplifying complex texts and medical letters.
    - **Vivifrail**: An application for managing physical exercise in frail cancer patients.
    - **Quality-Assured Portals**: Promotion of the use of platforms such as GuíaSalud (Spain) or the Austrian national health information portal (gesundheit.gv.at).
4. Organisational Self-Assessment: Use of the **OHL-Self AsseT tool** for healthcare centres to assess their own responsiveness and remove navigation barriers.

Table 7 shows the content analysed for the theme Digital Health Literacy.

Table 7. Content of theme Digital Health Literacy

Categories	Theme: Digital Health Literacy
Tools and strategies	**EU PROJECTS** **IDEAHL:** (Improving Digital Empowerment for Active Healthy Living) https://ideahl.eu/. Promoting healthier lifestyles within the European Union (EU), as well as improving health management and interaction with healthcare professionals through digital tools and initiatives. **UNCAN EU:** European plan against cancer (various flagship initiatives) - https://uncan.eu/a-role-for-patients-and-citizens/ **CAREWAY:** https://carewayproject.eu/: aims to improve cancer care literacy among underserved populations by co-creating reliable, accessible, and easy-to-understand educational resources in six European languages. Through participatory workshops, surveys, and capacity-building activities, the project will engage patients, citizens, healthcare professionals, and public health stakeholders in the citizens, support informed decision-making, and promote more inclusive cancer care development and testing of a multilingual Educational Toolkit. This toolkit, supported by a Training Kit for educators and a multi-format Digital Platform, will ensure broad accessibility and practical use. Local pilot sessions will refine the resources, while Policy Labs will foster knowledge exchange and generate a Policy Roadmap with recommendations for integrating inclusive cancer education into adult learning systems.

Categories	Theme: Digital Health Literacy
	Ultimately, CAREWAY seeks to empower citizens, support informed decision-making, and promote more inclusive cancer care. **CURTAIN:** https://curtainproject.eu/: aims to reduce cancer-related inequalities across Europe by improving cancer literacy at multiple levels: among citizens, patients, healthcare professionals, and organisations. CURTAIN will develop the first cancer-specific literacy tool for seven countries to guide literacy campaigns. It will also build the capacity of patients to navigate cancer care systems and technologies, focusing on vulnerable groups. Training for healthcare professionals, including doctors and nurses, will be developed, and Cancer Literacy Ambassadors will be selected to enhance communication between providers and patients. **PRAISE-U:** One of its aims is to carry out psychosocial research, analysing participants' perceptions and psychological impact in order to design a more humane and informative prevention strategy - https://uroweb.org/praise-u **HELEM-EU:** Development and Integration of Health Literacy with Innovative Methods in Medical Curricula in Europe. https://www.helemeu.org/es/ **Interact Europe 100:** Implemented in Austria which aims to develop interprofessional training in oncology. Due to high system fragmentation in Austria, this type of training focused on healthcare workers may be considered a good practice https://www.europeancancer.org/eu-projects/impact/interact-europe-100
	HEALTH LITERACY STRATEGIES **PyDeSalud** (https://pydesalud.com/): web platform (open and free) offering integrated services aimed at promoting knowledge, autonomy and active participation among citizens in caring for their health. **Digital Health Strategy of the Spanish Health System:** (https://www.sanidad.gob.es/areas/saludDigital/doc/Estrategia_de_Salud_Digital_del_SNS.pdf): aims to contribute to maintaining a good level of health among the Spanish population and to strengthening the public health system through the transformative power of digital technologies aimed at individuals, health professionals, healthcare service providers and other related agents. **Guidelines Salud.es** (https://portal.guiasalud.es/material-pacientes): provides materials for patients, family members, and carers to help them understand the recommendations of Clinical Practice Guidelines (CPGs) and Other Evidence-Based Products (OPBEs). They also provide information necessary to facilitate decision-making and improve doctor-patient communication. **Canal POC (Point Of Care):** (https://educacionpapps.blogspot.com/2024/04/que-es-una-canal-poc-point-of-care-en.html): A means or method used to provide relevant information and education to patients at the point of care. This type of channel is

Categories	Theme: Digital Health Literacy
	especially valuable in primary care and hospital settings, where information can be delivered effectively and timely to patients during their medical care. **Schwerpunkte** (Germany): OEPKG (The Austrian Health Literacy Alliance) website with key areas of health literacy. https://oepgk.at/schwerpunkte/ **INSEA** (Germany): is a generic peer led self-management programme (https://www.insea-aktiv.de/). **OPHELIA**: Optimising Health Literacy and Access. Is a process for improving health outcomes through authentic community consultation, meaningful engagement, and collaboration. Ophelia is the product of more than 20 years of research, evaluation, training, and practice. https://healthliteracydevelopment.com/who-developed-ophelia/
	CANCER HEALTH LITERACY STRATEGIES **Guidelines for Communication in Oncology. Spain**: Cross-cutting Issues and Care considerations (GuíaSalud y SESCS) (https://portal.guiasalud.es/wp-content/uploads/2025/09/ot_5_2_guias-de-comunicacion-en-oncologia_aspectos-transversales-y-durante-el-cuidado_def_sescs.pdf) **Symptom Navi**: Symptom Navi supports cancer patients in Switzerland in dealing with their cancer and the possible consequences of therapies and the disease. With Symptom Navi, it promotes partnership-based cooperation between cancer patients and specialists across the entire care chain. (https://symptomnavi.ch/de/) "Literacia em Oncologia: Todos contam!" "Literacy in Oncology: Everyone counts!" It is a collaboration between AEOP (Associação dos Enfermeiros de Oncologia de Portugal) and SPLS (Sociedade Portuguesa de Literacia em Saúde) focused on training professionals and teachers. The central premise, defended by the president of SPLS, highlights the importance of involving all stakeholders to promote health literacy, in addition to technical competences. (https://congresso.aeop.pt/2025/05/30/literacia-em-oncologia-todos-contam/) **Austria National Health Information Strategy**. Online health information portal that offers information about many different diseases including cancers in a quality-assured way (https://www.gesundheit.gv.at/index.html) Guia de Recursos para a Pessoa com Doença Oncológica e seus Cuidadores https://aicib.pt/2025/07/01/ja-esta-disponivel-a-2a-edicao-do-guia-de-recursos-para-a-pessoa-com-doenca-oncologica-e-seus-cuidadores **ListenIn proyect:** focuses on developing organisational cancer literacy with a specific focus on underserved communities confronted by cancer (people experiencing homelessness or housing exclusion or those without an active health insurance). Website: https://www.hcw.ac.at/forschung/projekte-und-aktivitaeten/listen-in-lebenswelt-orientiertes-und-systemisches-

Categories	Theme: Digital Health Literacy
	empowerment-fuer-obdach-wohnungslose-und-prekaer-wohnende-menschen-mit-krebskrankheitserfahrungen
	CANCER PROSTATE HEALTH LITERACY STRATEGIES **PSA Test** (https://www.nhs.uk/tests-and-treatments/psa-test/): análisis de sangre que ayuda a detectar afecciones de la próstata, como cáncer de próstata o agrandamiento de la próstata. **Risk checker** UK: https://prostatecanceruk.org/risk-checker: evaluador de riesgo. **Prostaatkanker.** Neetherlans. Website with interactive visual charts https://www.pharos.nl/begrijpjelichaam/kanker/prostaatkanker/#1 **Public health campaign Kestenijada:** dedicated to prostate cancer, has been implemented in Međimurje County. Croatia. **MitoHomes - ProstataHome**: Demystification strategy hosted on the Colombian League Against Cancer website. Informative microcapsules that deconstruct the main myths surrounding various types of cancer, including prostate cancer - https://www.ligacancercolombia.org/dia-mundial-del-cancer/#prostata . **Patients connecting together** AstraZeneca y AXXA seguros - Club Pro - Page with resources for prostate cancer patients on education, nutrition, healthy lifestyle with a family focus Patient community. Colombia. https://pacientesconectandojuntos.co/club-pro/#:~:text=Club%20pro%20%2D%20%C2%A1Bienvenidos%20a%20Conectando%20Juntos
	DIGITAL SKILLS European programme for the acquisition of digital skills that includes healthcare professions and is currently being developed in Spain, led by Unión Profesional and implemented by the professional associations. https://upro.es/ .
Good practices and initiatives	**WHO**: European Code Against Cancer. **Ministries of Health of member states**: Spain Network of Health Schools for **Citizens Regional strategies involving the third sector**: Government of the Canary Islands: Healthy Canary Islands **National strategies**: Network of Health Schools for Citizens Spain. **M-POHL**: promote programmes that involve citizen participation and professionals such as OPHELIA. **OCDE**: Health literacy for people-centred care publication European Commission
	"Health-Literate Health Centre": Adaptation of the Health Literate Organisations model (WHO/CDC) to Primary Care.
	OHL-Self AsseT: used in primary care. Developed in Switzerland

Categories	Theme: Digital Health Literacy
	Symptom Navi: Symptom Navi supports cancer patients in Switzerland in dealing with their cancer and the possible consequences of therapies and the disease.
Gaps and challenges	The evidence gathered shows that there continues to be an excessive focus on disease rather than health promotion, which limits citizens' ability to understand, anticipate and manage risks appropriately. Added to this is the lack of clear information to break down taboos, as well as the often-negative influence of social media, where misinformation circulates, amplified by the difficulty individuals have in identifying reliable sources and by growing mistrust of the healthcare system. All this is exacerbated by social inequalities, insufficient shared decision-making and variability in the quality of available digital information, which makes it difficult to understand complex medical content. In this context, it is essential to move towards tailored messages, with more accessible language (meer toegankelijk taalgebruik), and to promote initiatives that offer simple and easily accessible explanations, enabling people to make informed decisions and strengthening their ability to critically evaluate the content they encounter, especially in the digital environment.
Recommendations	Integrate health literacy throughout the entire care pathway (prevention/screening, diagnosis, treatment decisions, survival and palliative care), not just in campaigns.
	Mainly training for the general public and informal carers, as well as formal training on communicating with patients and their families.
	I would propose a set of five key questions that should be answered adequately by the population after training. The percentage of patients who visit a urologist, for example, is another parameter.
	It is important to involve the target population in order to better understand their needs and enable them to participate in the design of these interventions.
Resources and links	https://prostatecanceruk.org/risk-checker https://www.nhs.uk/tests-and-treatments/psa-test/ https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/ https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options https://www.europeancancer.org/content/european-code-of-cancer-practice.html https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions https://pubmed.ncbi.nlm.nih.gov/33352951/ https://academic.oup.com/eurpub/article/35/Supplement_4/ckaf161.267/8303201?login=false https://symptomnavi.ch/de/ https://gco.iarc.fr/en

Categories	Theme: Digital Health Literacy
	https://ideahl.eu/ https://cancer-code-europe.iarc.who.int/ https://www.alfabetizacionsalud.com/ https://pydesalud.com/ https://www.sanidad.gob.es/areas/saludDigital/doc/Estrategia_de_Salud_Digital_del_SNS.pdf https://portal.guiasalud.es/material-pacientes https://educacionpapps.blogspot.com/2024/04/que-es-una-canal-poc-point-of-care-en.html https://www.astursalud.es/noticias/-/noticias/proyecto-ideahl https://osasuneskola.osakidetza.eus/es/home https://www.easp.es/project/escuela-de-pacientes-2/ https://portal.guiasalud.es/wp-content/uploads/2025/09/ot_5_2_guias-de-comunicacion-en-oncologia_aspectos-transversales-y-durante-el-cuidado_def_sescs.pdf https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/cancer/docs/ESTRATEGIA_EN_CANCER_DEL_SNS.pdf https://www.madrid.org/bvirtual/BVCM017405.pdf https://prostatecanceruk.org/risk-checker https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata https://www.contraelcancer.es/sites/default/files/migration/actualidad/publicaciones/documentos/guiaprostata.pdf https://www.sciencedirect.com/science/article/pii/S1462388924000802 https://curtainproject.eu/ https://cancerpatientseurope.org/intervene/ https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/INEC/IETS/Cancer-prostata-final-pacientes%20final.pdf https://www.ligacancercolombia.org/cancer-de-prostata-3 / https://www.ligacancercolombia.org/dia-mundial-del-cancer/#prostata https://pacientesconectandojuntos.co/club-pro/#:~:text=Club%20pro%20%2D%20%C2%A1Bienvenidos%20a%20Conectando%20Juntos https://ex.movember.com/report-cards/index/report_category/prostate-cancer https://carewayproject.eu/ https://curtainproject.eu/ https://www.ligacontracancro.pt/educacaoi https://www.gesundheit.gv.at/index.html https://oepgk.at/#

3.2.3. Quality and comprehension of information

This topic is a source of concern for most of the key health informants who answered the general survey. A high level of consistency was observed across the different responses

during the analysis. The informants indicate that the quality of health information depends less on the quantity of materials available and more on whether these materials enable people to understand, make decisions, and act safely.

To achieve this, the need to standardise plain language is identified, as well as to reinforce accessibility through easy-to-read formats, multilingual versions, and non-digital options, and to ensure that the content is culturally adapted.

It also highlights the importance of co-creating materials with patients and with groups that are often left out, as well as placing information in everyday channels used by the public, not only in institutional spaces.

The analysis reveals gaps stemming from geographical heterogeneity, the use of technical and disease-focused language, and persistent difficulties in communicating risks in areas such as oncology. This underscores the need to incorporate readability criteria, cultural adaptation, and user participation as structural components of health communication.

Key aspects:

Respect all dimensions of health literacy

According to the WHO, HL refers to "the personal knowledge and competencies accumulated through daily activities and interactions, influenced across generations, and mediated by organisational structures and available resources that enable people to access, understand, appraise and use information and services to make decisions about health and well-being for themselves and those around them". This definition emphasises that HL does not depend exclusively on individual abilities, but also on how systems and organisations provide information that is understandable, usable, and tailored to people.

In light of this definition, the document shows that the quality of health information depends less on the volume of materials available and more on their ability to support understanding, decision-making, and action. Moving in this direction requires standardising plain language; ensuring accessibility through easy-to-read formats,

multilingual versions, and non-digital alternatives; and guaranteeing that the content is culturally adapted.

It is also necessary to co-create materials with patients and with groups that are often excluded from information planning, and to place messages in everyday communication channels, not only on institutional platforms.

The gaps identified, such as geographical heterogeneity, prevalence of technical language, difficulties in communicating risks in areas such as oncology, and the lack of continuity in information, reinforce the need to incorporate readability criteria, cultural adaptation, and active user participation as structural elements of communication aligned with all dimensions of HL described by the WHO.

Best communication practices

The health informants survey suggested various methodologies, communication formats, and experiences to improve communication. They are summarised below:

1. Combine tools that facilitate understanding with methodologies adapted to different audiences: In this regard, they highlight the use of the *teach-back* method, in which the professional asks the patient to explain in their own words what they understood. This allows the professional to confirm the clarity of the explanation without evaluating the patient. They also emphasise the systematic use of *plain language*, which focuses on organising information in a direct way, using simple sentences and avoiding technical jargon. This supports the proposal to institutionalise its use in screening materials and informed consent documents, validating them with patients as well before dissemination.

2. Diversify formats and channels: Tools such as surveys and public consultations are mentioned and illustrated by examples like the Youth Barometer or national consultation processes on literacy strategies, which help tailor messages based on an understanding of population perceptions. Debates, panel discussions, and testimonials are also included, such as those developed by the Andalusian School of Public Health, which

generate multi-format materials, such as podcasts, videos, and informational pieces, useful for diverse audiences.

3. Social mediators and key community stakeholders: These are influential individuals capable of conveying information in an understandable way. This strategy is complemented by the incorporation of other spheres such as sports or the arts to address beliefs and social representations, drawing on frameworks like the *Health Belief Model*, which helps address myths and imaginaries related to health through experiences that feel familiar to the public.

4. Successful experiences: Best practices also include applied initiatives that combine accessibility, multichannel approaches, and community participation. Among them is VIVIFRAIL, an application aimed at frail older adults to promote physical activity, which exemplifies the use of digital tools adapted to specific populations. Another example is "2 Minutes to Change Your Life", a transmedia campaign that uses fiction series, websites, mobile apps, social media, in-person sessions, and educational materials to disseminate knowledge on prevention and non-communicable diseases. Finally, the "Com a saúde não se brinca" program, based on live seminars broadcast on YouTube, shows how open digital formats can facilitate awareness-raising and information exchange between the public and professionals, integrating interactive approaches into public health communication.

Co-design: the most effective communication tool

Co-creation and co-design involve patients and the public from the very beginning, ensuring that materials respond to what a person needs to know and do in their daily life. This results in messages written in plain language, with easy-to-read features, visual supports, and multilingual versions that are validated with users and proposed as a public-system standard to reduce territorial variability.

In complex areas such as oncology and prostate screening, joint design guides the development of decision aids and question checklists that explain risks and next steps. It also makes it possible to adapt content to different cultural and linguistic contexts (migrants, older adults, people with low literacy, and people with disabilities) and to

choose everyday communication channels, such as media, social networks, and community settings, rather than focusing solely on institutional websites.

Through this approach, information shifts from simply "being available" to becoming truly usable for understanding, decision-making, and action.

Table 8 shows the content analysed for the theme Quality and Comprehension of Information (see original verbatim text in Annex 8 - Verbatim quotes - Quality and comprehension of information).

Table 8. Content of theme Quality and Comprehension of Information

Topic	Theme: Quality and Comprehension of Information
Tools and Strategies	**Tools and approaches that facilitate understanding of information** **Teach-back method** The Teach-back method is an evidence-based health communication technique in which the professional asks the patient to explain, in their own words, what they have understood after receiving instructions. The aim is not to evaluate the patient but to assess the clarity of the professional's explanation.
	Plain Language Plain language refers to clear and concise writing designed so that readers understand the message the first time they read it. It focuses on the needs of the audience by using simple vocabulary, direct sentence structures, and logical organisation, avoiding jargon and unnecessary complexity. **Institutionalising plain language** One proposed strategy is to require by law that all informed consent documents and screening materials be written in plain language and validated by patients.
	Use of multiple channels to reach and engage the population Different formats can help information reach people and raise awareness. For example, surveys among young people such as the Youth Barometer, which collects the opinions of young people (15–25 years old) annually and has incorporated health literacy questions. National consultations can also be used, such as the Australian National Health Literacy Strategy Framework consultation. https://consultations.health.gov.au/national-preventive-health-taskforce/national-health-literacy-strategy-framework-consul/
	Debates, literacy dialogues and testimonies Alternative communication approaches include debates, literacy

Topic	Theme: Quality and Comprehension of Information
	dialogues and personal testimonies. Institutions such as the Andalusian School of Public Health have used these formats to produce multi-format educational materials, including podcasts, videos and other media.
	Careful translation into local and adapted languages Special attention must be paid to translation into local languages and culturally adapted formats.
	Co-creation with end users Co-creation and the participation of end users throughout all stages of development is one of the most effective ways to ensure linguistic and cultural adaptation.
	Incentives and feedback initiatives Establishing incentives, awards and innovative feedback mechanisms can encourage good practices. For example, a health literacy competition organised by the Patients' School and the Andalusian School of Public Health rewarded best practices in health literacy interventions. Both team-based initiatives and technology-based projects were recognised. The most relevant initiatives were selected and the five best were publicly presented and evaluated by a jury.
Tools and Strategies	**Use of influencers and trusted communicators** The involvement of influential individuals who are able to adapt, translate and communicate information in non-technical language can help broaden the reach and understanding of health information**.**
	Incorporating other spheres such as sports and the arts Integrating health topics into other domains such as sports, culture and the arts can help address health issues from complementary perspectives. One example is the ***Health Belief Model*****,** which incorporates concepts from the sociology of health, including beliefs, myths and social perceptions related to health. https://www.sciencedirect.com/topics/medicine-and-dentistry/health-belief-model
Best Practices	**VIVIFRAIL** An application adapted for frail older adults to support physical exercise and promote healthy ageing. https://vivifrail.com/es/documentacion/
	"2 Minutes to Change Your Life" A transmedia health education campaign promoting accessible knowledge and behavioral change to prevent cancer and other non-communicable diseases. The series uses storytelling and entertainment to address cancer-related issues. Broadcast on RTP1

Topic	Theme: Quality and Comprehension of Information
	during prime time, it represents the first health education series aired on Portuguese television. The 20-episode series provides practical information and encourages viewers to reflect on their behaviour and consider lifestyle changes. To reach the whole population, the campaign also uses multiple formats and platforms, including a website, mobile applications (iOS and Android), social media with exclusive interactive content, face-to-face sessions across the country, and educational materials used in schools alongside an online course. http://www.2minutos.pt
	"Com a saúde não se brinca" The "Health Is No Joke" program is a series of live webinars, broadcast on SPLS's YouTube channel, that aims to raise awareness and educate the public and healthcare professionals on crucial public health issues. With an interactive and enlightening approach, the program aimed to foster health literacy and promote preventative behaviors among its participants. https://splsportugal.com/events/spls-organiza-ciclo-de-webinares-sobre-vacinacao-cardiologia-e-saude-mental-inscreva-se-aqui/
Gaps and Challenges	Health information is often presented in highly technical language focused on disease and clinical terminology rather than on what people actually need to understand in order to manage their daily situation. This creates a common paradox: brochures, websites and information resources exist, but they do not necessarily help people make decisions because they do not clearly explain the practical meaning of the information, what it implies for the individual, what options exist or what concrete actions might be considered.
	In oncology, this lack of clarity is intensified because decisions are often complex and surrounded by uncertainty. Many people do not fully understand treatment alternatives, side effects, impacts on quality of life or the support systems available, especially when the process is long or becomes chronic. Information is also frequently delivered at specific moments, such as at diagnosis, when understanding actually requires continuous support throughout the entire care pathway. People need time and space to ask questions, review information and confirm their understanding. Without this continuity, information remains a "data point" rather than becoming real capacity for decision-making.
	The consequence is that the challenge is not only to provide information but to make it understandable and safe for decision-making. This requires clear language formats, easy-to-read materials, visual support and multilingual versions when necessary,

Topic	Theme: Quality and Comprehension of Information
	as well as non-digital alternatives for those who cannot or prefer not to rely on digital technologies. Another critical need is improving risk communication. For example, in prostate cancer it can be difficult to explain probabilities, false positives and negatives, and the risks of overdiagnosis or overtreatment associated with PSA testing. Without appropriate tools and training, shared decision-making may remain limited in practice, meaning that patients receive information but not necessarily understanding or real control over the next steps.
Recommendations	Communication standards based on health literacy principles should be established within public health systems so that clear language, accessibility and user orientation become part of how services operate rather than depending on the initiative of individual professionals.
	It is also recommended to move beyond traditional healthcare settings and bring information to places where people do not usually seek health information. Health spaces are often visited after a disease appears rather than beforehand. For messages to reach people in time, they must be more accessible and take into account cultural context, socioeconomic realities and existing barriers. Attractive communication tools and credible messengers can reinforce trustworthy sources and facilitate verification of information.
	It is essential not only to design materials *for* the population but to co-create them *with* the population. Patients and citizens should be actively involved in exploration and design processes. Particular attention should be given to groups that are often excluded, such as migrants, older adults, people with low literacy, people with disabilities and minority communities.
Resources and Links	https://www.sciencedirect.com/topics/medicine-and-dentistry/health-belief-model https://vivifrail.com/es/documentacion/ https://www.astursalud.es/categorias/-/categorias/profesionales/01000practica-clinica/03000programas-de-deteccion-y-prevencion/02000programas-de-deteccion-precoz-cancer https://splsportugal.com/events/spls-organiza-ciclo-de-webinares-sobre-vacinacao-cardiologia-e-saude-mental-inscreva-se-aqui/ http://www.2minutos.pt https://consultations.health.gov.au/national-preventive-health-taskforce/national-health-literacy-strategy-framework-consul/

3.2.4. Clinical communication and shared decisions

This section compiles the contributions of the key health informants regarding clinical communication and shared decision-making.

Thirty-six mentions have been analysed, which, although sometimes intertwined with other dimensions of the analysis, contain a key idea or greater emphasis on the topic of shared decision-making. The results have been grouped into tools and strategies, good practices and initiatives, gaps and challenges, and recommendations.

The content identifies that risk communication and understanding of treatment options are critical points in complex clinical processes, especially in oncology, where uncertainty and the long-term effects of decisions play a role.

There are frameworks and guidelines on shared decision-making, although their application is uneven due to lack of time, training and availability of specific tools. Resources such as decision-making aids, guidelines, protocols and organisational models in different countries are described.

The gaps identified include difficulties in understanding, myths, inequalities and a lack of adapted materials. Structural deficits in effective communication in oncology are also highlighted. The recommendations propose strengthening dissemination channels, developing decision-making tools, improving information on treatments and promoting access to reliable resources from primary care.

Key aspects:

European frameworks providing the theoretical and technical basis

On this occasion, the informants did not provide as robust and extensive a framework as in the previous sections. The contributions are more limited, but it is worth mentioning those that do exist:

- **International organisational models and operational frameworks**. Healthcare system strategies that articulate patient participation:
  - NHS England – Operational models focused on decision-making with the patient at the centre of the process.

https://www.england.nhs.uk/eolc/personalised-care/

- NHS England – Guide to assessing support for self-care and shared decision-making. https://www.england.nhs.uk/personalisedcare/supported-self-management/health-system-support-framework-for-supported-self-management/

- **Documents setting out general principles and recommendations on shared decisions**:
  - European Code of Practice in Oncology (Includes a specific section on shared decision-making). https://www.europeancancer.org/content/the-code-shared-decision-making
- **Regional strategies and models**. Regional institutional initiatives that structure intervention:
  - Cancer Management Strategy 2022–2028 – Galicia. Places cancer patients at the centre of the process and promotes clinical decisions based on fluid communication. https://www.sergas.gal/Asistencia-sanitaria/Documents/1635/Estrategia_de_gestion_del_cancer_en_Galicia_22-28.pdf
  - Shared decision-making model – Catalonia (End-of-life care). https://decisionscompartides.gencat.cat/es/decidir-sobre/atencio-final-vida/
- **Initiatives that offer specific resources to support understanding of treatment options**:
  - Shared Decision-Making Support Tool for Prostate Cancer. https://www.madrid.org/bvirtual/BVCM017405.pdf
  - AECC – Practical Guide to Prostate Cancer. Provides information about the disease and side effects to facilitate decision-making. https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata

Good practices that serve as a guide for institutions

Shared decision-making has also been a source of concern for international organisations, which have produced a set of documents and frameworks that provide guidance on the provision of clear information, access to reliable content and the integration of shared decision-making into health systems

- **Council of Europe – Health literacy guides and good practice frameworks**. These emphasise the importance of providing clear health information, improving access to reliable content, and promoting shared decision-making in screening, treatment, and end-of-life care. https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75

- **European Cancer Organisation – "Cancer literacy: Informing patients and implementing shared decision making".** Work that includes recommendations applicable to prostate cancer to improve health literacy, participation, and shared decision-making. https://www.sciencedirect.com/science/article/abs/pii/S2213538322000546?dgcid=author

- **NICE – Standards framework for shared-decision-making support tools.** Standard framework for the development and use of decision-making support tools, including specific aids for patients. https://www.nice.org.uk/corporate/ecd8

Best practices that serve as a guide for patients

The informants highlighted some of the tools that provide direct assistance in decision-making as best practices. These initiatives allow for the integration of personalised information, understanding of treatment options, and facilitate the assessment of risks and benefits.

- **Knowing Your Options**. Allows users to enter personal clinical parameters (PSA and other results) and generates an analysis of therapeutic options with individualised risks and benefits.

https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options

- **MacMillan Cancer Support**. **Information for therapeutic decisions**. Provides structured resources to understand treatment options and facilitate informed decisions. https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions

- **Share to Care (Germany).** Comprehensive programme that supports joint medical decisions between patients, doctors and nurses, with components that structure the shared decision-making process. https://share-to-care.de/

An uninformed patient cannot make a decision. Time and accurate information are needed.

Shared decision-making depends on the patient's understanding the risks and treatment options. The responses indicate that communicating risk is a critical issue and that, without a clear understanding of alternatives, long-term effects and levels of uncertainty, the decision-making process cannot truly be shared.

When information is presented at emotionally charged moments or offered without sufficient time to review and ask questions, the patient receives data but cannot transform it into useful elements for decision-making. The information emphasises that this situation is particularly prevalent in oncology.

That is why there are still many areas for improvement. The recommendations focus on strengthening communication through hybrid actions that combine face-to-face events with new digital media. It is proposed to develop decision-making aids that include information on the long-term effects of treatments. It is also recommended to encourage family doctors to prescribe links to users and patient resources to facilitate access to reliable information.

The proposals aim to strengthen knowledge about treatments, improve information resources, and expand access to decision-making tools to facilitate informed choices.

Table 9 shows the content extracted from the theme Clinical communication and shared decisions (see more information in Annex 9 - Verbatim quotes - Clinical communication and shared decisions).

Table 9. Content of theme Clinical communication and shared decisions

Categories	Theme: Clinical communication and shared decisions
Tools and strategies	Shared Decision-Making Tool for Prostate Cancer https://www.madrid.org/bvirtual/BVCM017405.pdf
	Practical Guide to Prostate Cancer Contains clear information and side effects to aid decision-making https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata
	European Code of Practice in Oncology Contains a specific section on Shared Decision Making https://www.europeancancer.org/content/the-code-shared-decision-making
	2022-2028 Cancer Management Strategy of the Galician Regional Ministry of Health. The strategy prioritises placing cancer patients at the centre of the process, promoting clinical decisions that are not unilateral, but based on fluid Communication https://www.sergas.gal/Asistencia-sanitaria/Documents/1635/Estrategia_de_gestion_del_cancer_en_Galicia_22-28.pdf
	Shared decision-making in Catalonia at the end of life https://decisionscompartides.gencat.cat/es/decidir-sobre/atencio-final-vida/
	National Health Service England have operating models that recognise the importance of empowering patients to be at the heart of decision making. https://www.england.nhs.uk/eolc/personalised-care/ NHS England produce a guide on evaluating these areas https://www.england.nhs.uk/personalisedcare/supported-self-management/health-system-support-framework-for-supported-self-management/
Good Practices and Initiatives	**Health literacy guides and good-practice frameworks developed by the Council of Europe** highlight the importance of providing clear health information, enhancing access to reliable content and promoting shared decision-making within health systems, which are essential components for informed prostate cancer screening decisions, treatment choices and end-of-life care discussions. https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75

Categories	Theme: Clinical communication and shared decisions
	European Cancer Organisation: **'Cancer literacy – Informing patients and implementing shared decision making'** This work includes recommendations that could be adapted to prostate cancer contexts to promote better health literacy, patient engagement and shared decision-making https://www.sciencedirect.com/science/article/abs/pii/S2213538322000546?dgcid=author
	Guides NICE. National Institute for Health and Care Excellence. Standards framework for shared-decision-making support tools, including patient decision aids. https://www.nice.org.uk/corporate/ecd8
	Knowing Your Options allows newly diagnosed patients, who are faced with several different treatment options, to enter their own personal cancer parameters, such as PSA and other test results, into a secure web link that analyses their data and establishes their full range of options, with risks and benefits specific to that individual. https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options
	Mac Millan Cancer Support: helps you understand treatment options. https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions
	Share to Care (Germany): supports individuals in making medical decisions together with their doctors and nurses, decisions tailored to their needs and life situation. The comprehensive programme consists of several components and promotes shared decision-making. https://share-to-care.de/
Gaps and challenges	Work on the concept of literacy, understanding that literacy is not just about providing information, but also about developing comprehension, critical thinking, comparing options and making decisions consistent with values.
	The need to institutionalise health literacy as part of standard care and to involve patients in decision-making in oncological processes is highlighted, pointing out that there are false myths and ignorance about the real risks, and that communication with the doctor does not always allow for an approach that promotes joint decision-making.
	Challenges related to health literacy are also described in other cancers such as breast cancer, where emotional stress, misconceptions, and poor ability to understand complex information can hinder participation in screening programmes or informed decision-making about treatment. It is indicated that neither the patient nor their family receive adequate guidance and that there is not enough time for this during the consultation. It also points out that there are inequalities in understanding and access, that health literacy is not evenly distributed, and that there may be information overload at the time of diagnosis, with large volumes of information, complex language and statistics, and little time to absorb, reflect and ask questions.
	The main gaps include unequal access to understandable information, a lack of culturally and linguistically adapted materials, and insufficient

Categories	Theme: Clinical communication and shared decisions
	training of professionals in effective communication, and oncology, and specifically in prostate cancer, challenges are mentioned in supporting informed decision-making, understanding the risks and benefits of screening and treatment, and education about palliative care, noting that the challenge lies in adapting information to each user's literacy level, and that the challenge lies in communicating with the patient, in the use of new technologies and AI, and in the critical level of health literacy, and that there is a low level of knowledge among men that hinders prevention, early diagnosis through PSA screening, and informed decision-making.
Recommendations	Hybrid dissemination actions are proposed through the creation of events with patients, prepared through new media, so that the event acts as an anchor and the dissemination of information revolves around it.
	The development of tools to aid decision-making on treatment is proposed, so that doctors are aware of the long-term damage caused by the therapies implemented and can convey this important information when decisions are made.
	It is recommended that family doctors be encouraged to prescribe links to resources such as user and patient schools, such as the Galician School of Health for Citizens, and that these resources be made much more widely available. With more reliable information, better decisions can be made.
Resources and links	https://decisionscompartides.gencat.cat/es/decidir-sobre/atencio-final-vida/ https://www.europeancancer.org/content/the-code-shared-decision-making https://www.sergas.gal/Asistencia-sanitaria/Documents/1635/Estrategia_de_gestion_del_cancer_en_Galicia_22-28.pdf https://share-to-care.de/ https://www.england.nhs.uk/eolc/personalised-care/ https://www.england.nhs.uk/personalisedcare/supported-self-management/health-system-support-framework-for-supported-self-management/ https://www.nice.org.uk/corporate/ecd8 https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75 https://www.sciencedirect.com/science/article/abs/pii/S2213538322000546?dgcid=author https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata https://www.europeancancer.org/content/european-code-of-cancer-practice.html https://prostatecanceruk.org/risk-checker https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions https://www.madrid.org/bvirtual/BVCM017405.pdf https://pubmed.ncbi.nlm.nih.gov/33568208/ https://www.krebshilfe.de/informieren/ueber-krebs/

3.2.5. Prostate cancer screening

Although the initial questionnaire did not include a specific question on prostate cancer screening, this has emerged as a recurring theme in the content analysis and has therefore been assigned a dimension in its own right.

Table 13 brings together initiatives, resources and observations on prostate cancer screening in different contexts, in a scenario marked by a central discrepancy: the absence of scientific consensus on the advisability of a population-based screening programme, due to the lack of a test with adequate sensitivity and specificity for universal use and the fact that PSA screening reduces advanced tumours but increases the detection of localised cancers without demonstrating a consistent reduction in mortality. Based on this structural uncertainty, tools and strategies are described that seek to support informed decision-making, good practices aimed at facilitating access to understandable information, gaps that explain the current heterogeneity of opportunistic screening, and recommendations focused on research into markers, risk stratification, and clear individualised decision-making pathways.

Tools aimed at facilitating understanding and decision-making are listed: storytelling cards for population-based programmes in the Netherlands; PGUIDE (Erasmus MC) with tools for raising awareness and supporting decisions about prostate screening; INSIDERS, which develops interventions in screening programmes to improve health literacy responses; references to national screening programmes with free, high-quality information materials (breast and colorectal, Germany); and Slovenia's National Health Literacy Strategy 2025-2035, which aims to promote existing and planned screening programmes (prostate and lung).

Included are a risk checker (Risk Checker UK) for self-assessment; official NHS resources on PSA testing; a publication evaluating the usability of an interactive Option Grid for prostate screening and the lessons learned; and public campaigns by the Egyptian Ministry of Health targeting men for early detection and PSA screening.

Key aspects:

Controversy surrounding the evidence and relevance of population screening and the test used

While some respondents highlight and value population screening, such as the high-level recommendation from the WHO (linked to the European Plan to Combat Cancer) or the multiple national government strategies that develop population screening programmes, other respondents comment on opportunistic screening with PSA, mentioning that there is awareness of the test, but a lack of clear information on its recommendation, conditions and ages, as well as the absence of algorithms for its management (that of PSA).

Another controversy is the iatrogenic effects it causes, with heterogeneous actions leading to healthcare overload, excessive biopsies, false positives, overdiagnosis and overtreatment, and associated costs; and the need for rigorous information for men.

In summary, PSA screening reduces advanced tumours and increases localised tumours without demonstrating a consistent reduction in mortality, which is why most guidelines recommend discussing the test with men aged 55-69 or earlier if there are risk factors, explaining the benefits and harms and leaving the decision to the patient. There is no universal recommendation for a population-based programme.

Recommendations for the future

Technologies such as genetic testing are suggested to improve risk stratification, but there is no consensus on universal screening. Active early detection in at-risk groups is proposed as an option after informed discussion.

Key informants pointed out that there is currently no test with adequate sensitivity and specificity for universal screening. PSA testing has benefits and harms that must be discussed individually. This lack of a validated tool is at the heart of the current disagreement about screening and shapes the structure of the recommendations.

Table 10 shows the content extracted from the theme Prostate cancer screening (see more information in Annex 10 - Verbatim quotes - Prostate cancer screening).

Table 10. Content of theme Prostate cancer screening

Categories	Theme: Prostate cancer screening
	Neederlands: Storytelling cards for population screenings. https://preventiemethodieken.be/vertelkaartjes-verloop-bevolkingsonderzoek-baarmoederhalskanker
	PGUIDE project (led by Erasmus Medical Center), Tools to raise awareness about prostate cancer risk and help people decide whether or not to undergo screening. www.gezondheidsvaardigheden.nl
	"INSIDERS" develops various interventions within existing screening programs to improve responsiveness in health literacy. https://pure.amsterdamumc.nl/en/persons/mirjam-fransen/.
	National Screening programs Official screening programmes, most notable Breast cancer, Colorectal cancer, are high quality and free information support leaflets available. https://www.g-ba.de/service/versicherteninformationen/frueherkennungsuntersuchungen/ Slovenia's National Health Literacy Strategy 2025-2035, as well as the accompanying Action Plan 2025-2027, includes increased promotion of existing cancer screening programs, as well as planned programs (prostate and lung cancer).
Good practices and initiatives	**Risk checker UK**: Website for conducting a risk self-assessment. https://prostatecanceruk.org/risk-checker
	PSA Test. National information on PSA screening tests. https://www.nhs.uk/tests-and-treatments/psa-test
	Publication: User-testing an interactive option grid decision aid for prostate cancer screening: lessons to improve usability: https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/
	Ministry of Health and Population (MoHP). Egypt Runs public health campaigns targeting men for early detection, PSA screening
Gaps and challenges	Highest-level institutional recommendation: WHO: Implementation of the European Plan to Combat Cancer of 22 September 2022. It called on Member States to introduce new screening programmes, including for prostate cancer.
	The need for a prostate cancer screening test that meets the required sensitivity and specificity criteria is highlighted, noting that no such test currently exists. Increasing access to less harmful and safer treatments available for prostate cancer is also identified as a challenge.
	An important challenge is mentioned in colon cancer and prostate cancer in relation to screening protocols, comparing them with breast cancer screening in the Autonomous Community of the Canary Islands, Galicia, etc.
	In opportunistic prostate cancer screening with PSA, it is indicated that men are aware of its existence but lack clear information on whether it is

Categories	Theme: Prostate cancer screening
	recommended, under what conditions and at what ages, and it is pointed out that there is a need to know when and how screening should be carried out, indicating that it is not structured.
	It describes the absence of clear algorithms for managing PSA testing in opportunistic screening, which has led to inconsistent practices, overburdening of clinical pathways that are unprepared for the referral of asymptomatic men, excessive biopsies, a large number of false positives, and overdiagnosis and overtreatment of indolent lesions, with high associated costs. and affirms the need for clear and rigorous information for men about prostate cancer and what to expect from screening.
Recommendations	Population-based information policies and educational campaigns conducted by medical professionals and primary care physicians on PSA screening in adults are proposed, along with online and social media campaigns on platforms such as Facebook, Instagram, and TikTok for health education and to improve participation in screening programmes, and awareness campaigns on the importance of early screening and maintaining healthy lifestyles to reduce the risk of onset.
	It is proposed to promote research into cancer markers that can be used as a screening test in population screening, and it is noted that the scientific evidence on prostate cancer screening is controversial, as it reduces the detection of advanced tumours and increases the detection of localised cancers, but it has not been shown to clearly and consistently reduce overall mortality or prostate cancer mortality in large studies due to the harms of overdiagnosis and overtreatment. Most guidelines recommend discussing PSA and digital rectal screening with men between the ages of 55 and 69, or earlier if there are risk factors such as black race or family history, informing them of the benefits and risks and leaving the final decision to the patient, with no universal recommendation for general population screening, It is mentioned that new technologies such as genetic testing, for example for BRCA mutations, could improve risk stratification, although there is no consensus for universal population screening and active early detection may be beneficial in risk groups after a discussion of risks and benefits for an informed decision, also pointing out the need to insist on scientific evidence for prostate cancer screening.
	It is noted that, in the digital sphere, patients rely heavily on social media such as Facebook and YouTube and on individual doctors' or hospitals' websites, and that there are no official digital platforms offering evidence-based tools in Arabic for prostate cancer screening, treatment decision-making or palliative care. It is mentioned that there may be a taboo surrounding prostate cancer screening as an additional barrier, that not all healthcare professionals are familiar with health skills or competencies, that it is important to be aware of the reality of opportunities for access to diagnosis and treatment in each country, and that for colon cancer, detection by letter or through the general practitioner with an iFOBT test is mentioned, along with the proposal for

Categories	Theme: Prostate cancer screening
	standard PSA screening by the family doctor through blood tests from a certain age onwards.
Resources and links	https://prostatecanceruk.org/risk-checker https://www.nhs.uk/tests-and-treatments/psa-test/ https://preventiemethodieken.be/vertelkaartjes-verloop-bevolkingsonderzoek-baarmoederhalskanker www.gezondheidsvaardigheden.nl https://pure.amsterdamumc.nl/en/persons/mirjam-fransen/ https://www.g-ba.de/service/versicherteninformationen/frueherkennungsuntersuchungen/ https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/

3.2.6. Evaluation and research

As a general summary of this topic, a set of tools, initiatives and recommendations related to health literacy assessment and research are included.

The section on tools and strategies presents instruments for measuring digital literacy, assessments of navigability and comprehension in cancer survivors, organisational self-assessment tools and university projects to validate health applications and educational materials. Good practices include quality standards, resources for programme evaluation, studies on national literacy policies, and specific surveys on quality of life in prostate cancer. The gaps identified refer to difficulties in assessing the credibility of online information, limitations of measurement tools and lack of robust indicators, along with a scarcity of longitudinal studies and difficulties in measuring the real impact on health and equity.

Finally, the recommendations focus on broadening the scope of evaluation beyond knowledge, investing in applied research, establishing national strategies with monitorable indicators, analysing impact and return on investment, and promoting the use of reliable sources to facilitate informed decision-making.

Key aspects:

Scientific and technical support for the analysis of digital literacy in health

There are methodologies and tools identified as guidelines and best practices for assessing health literacy. Incorporating them into everyday use is seen not only as a bonus in terms of quality, but also as a necessity, so that literacy becomes increasingly scientifically sound.

Identified gaps refer to difficulties in assessing the credibility of online information, limitations of measurement instruments and lack of robust indicators, along with a scarcity of longitudinal studies and difficulties in measuring the real impact on health and equity.

Tools for measuring and evaluating health literacy:

- **The IDEAHL strategy** includes a specific module of indicators to measure and monitor digital literacy in health, with methodological guidelines applicable to different contexts. This tool is complemented by the assessment of digital and navigational literacy in cancer survivors using Swiss instruments.

- **HLS19**, one of the scales for measuring digital health literacy that allows for the analysis of comprehension and navigation skills in digital health environments.

- **OHL Self AsseT**, a tool designed to assess primary care and improve organisational literacy, focused on facilitating navigation, understanding and use of services. It has already been tested in general medical practices and home care organisations in Switzerland. In the hospital setting, there is an international self-assessment tool.

- **OHL Hos**, designed to measure the organisational responsiveness of hospitals in terms of accessibility and understanding.

- **NICE Quality Standards** offer a library of over two hundred standards and a set of indicators that enable the definition and measurement of quality in health, public health and social care, including a specific standard for prostate cancer (QS91).

- **California's Self-Management Resource Centre (SMRC)** provides validated questionnaires that are useful for measuring outcomes in health education programmes.

- **M-POHL** brings together products from the EVPOP project on national health literacy policies, offering practical resources to support the development and strengthening of policies and environments that facilitate the understanding and use of health information.

It is interesting to highlight some scientific articles that the informants have pointed out, given that health actions and policies need to be based on evidence:

- **Zdravko, guidelines for the development of digital literacy.** Makarov DV, Feuer Z, Ciprut S, Lopez NM, Fagerlin A, Shedlin M, Gold HT, Li H, Lynch G, Warren R, Ubel P, Ravenell JE. Randomised trial of community health worker-led decision coaching to promote shared decision-making for prostate cancer screening among Black male patients and their providers. Trials. 10 February 2021;22(1):128. doi: 10.1186/s13063-021-05064-4.

- **EUROPROMS (Europa Uomo Patient Reported Outcome Study) STUDY** is the first ever prostate cancer quality of life survey conducted by patients for patients. Design, setting, and participants: A cross-sectional survey was conducted among PCa patients currently receiving or having received treatment. https://www.europa-uomo.org/who-we-are/quality-of-life-2/the-euproms-study/

The challenge: What should be measured?

The first issue is the credibility of online information. The evidence gathered identifies the difficulty in distinguishing reliable sources and suggests creating and maintaining official pages that act as thematic reference points. Measurement should include the use and reach of these portals, content traceability (authorship, updates and references) and levels of interaction with campaigns that guide users towards verified sources. This

approach makes it possible to assess whether citizens are finding adequate information and whether guidance mechanisms are fulfilling their function.

A second axis concerns the validity and focus of measurement instruments. Existing instruments often focus on reading and literal comprehension, leaving out key dimensions of the decision-making process. The document proposes expanding the assessment framework to measure actual capacity to understand, decide and act, incorporating practical understanding of clinical materials, informed choice, measures of experience and outcomes perceived by patients, as well as decision conflict. For these data to be useful in equity policies, they need to be systematically disaggregated by vulnerable groups and monitored over time.

In relation to the real impact on health and equity, the evaluation must go beyond traditional clinical indicators and collect data on variations by age, educational level, socioeconomic status, origin and territory. The analysis should link literacy interventions with service use (e.g., emergency rooms and unscheduled consultations), treatment adherence, and changes in quality of life, incorporating estimates of return on investment to adjust the scale and design of programmes. This analysis makes it possible to decide which interventions to sustain, which to adapt, and where to focus resources.

Applied research should identify which formats, messages, and settings are most effective in facilitating understanding and decision-making. The document prioritises comparing face-to-face, digital and community-based modalities, incorporating interactive virtual programmes and evaluating their effective reach. It also recommends involving patients and citizens in design and evaluation and using self-care and literacy programme tools to measure reach and effectiveness. This type of research guides operational decisions about which channels to maintain, which content to adjust and which combinations produce the best results.

The performance of health systems requires indicators that measure the extent to which organisations enable people to understand information, navigate services and participate in decisions. The proposal includes assessing the readability of materials, the availability of comprehension aids (e.g. interpreters or easy-to-read formats), time and space for

questions and confirmation of understanding, as well as the existence and use of decision aids and records of shared decision-making processes. These elements offer a structural view of the environment in which decisions are made.

At the level of governance and political organisation, key health informants propose explicitly stating the value of health literacy within national strategies and action plans with concrete measures and regular monitoring. It is suggested that measurement systems be aligned with validated indicators at the European or national level, the impact of campaigns be evaluated, and stable funding be ensured to scale up verified good practices, avoiding the implementation of unevaluated interventions. Monitoring should consider compliance with plans, comparability of results, and financial sustainability of those initiatives with proven effectiveness.

Finally, in specific areas such as prostate cancer screening, the recommendation is to continue measuring risk and benefit understanding, levels of informed choice by risk groups, and the use of decision aids, linking this data to clinical outcomes such as stage at diagnosis and overuse of tests. Research into markers is presented as a priority area, with evaluation as a basis for deciding on scaling, targeting and updating protocols, as already described in the section on prostate cancer screening.

The content of the theme Evaluation and research can be seen in Table 11 (see more information in Annex 11 - Verbatim quotes - Evaluation and Research).

Table 11. Content of theme Evaluation and research

Categories	Theme: Evaluation and Research
Tools and Strategies	**IDEAHL** European Digital Health Literacy Strategy Includes a specific module with indicators for measuring and monitoring digital health literacy. https://zenodo.org/records/11395540
	Digital and navigational health literacy assessment in cancer survivors: using Swiss HLS19 Instruments Study using the Swiss HLS19 instruments to assess digital and navigational health literacy in cancer survivors. https://academic.oup.com/eurpub/article/35/Supplement_4/ckaf161.267/8303201?login=false

Categories	Theme: Evaluation and Research
	OHL-Self AsseT A tool used in primary care to evaluate and improve organizational health literacy (OHL), focusing on making services easier to navigate, understand and use. It has been tested in Switzerland in general practitioner practices (GPPs) and home-care service organizations (HCSOs). https://pubmed.ncbi.nlm.nih.gov/33352951/
	International Self-Assessment Tool for Organizational Health Literacy (Responsiveness) of Hospitals (OHL-Hos) https://www.hphnet.org/wp-content/uploads/2021/08/SAT-OHL-Hos-v1-0-EN-international_update1.1.pdf
	German Center of Cancer Research and the website of the German Cancer Website that display studies on cancer. https://www.krebshilfe.de/informieren/ueber-krebs/
	Scientific publications Zdravko, smjernice za razvoj digitalne pismenosti Makarov DV, Feuer Z, Ciprut S, Lopez NM, Fagerlin A, Shedlin M, Gold HT, Li H, Lynch G, Warren R, Ubel P, Ravenell JE. Randomized trial of community health worker-led decision coaching to promote shared decision-making for prostate cancer screening among Black male patients and their providers. Trials. 2021 Feb 10;22(1):128. doi: 10.1186/s13063-021-05064-4. PMID: 33568208; PMCID: PMC7876807 https://pubmed.ncbi.nlm.nih.gov/33568208/
	Joint studies with universities for validation of apps and health education tools. Example: collaborations with the University of Cádiz or research institutes such as Instituto de Salud Carlos III, for example in the validation of MiCardiApp.
Good Practices and Initiatives	**Quality Standards NICE** Provides a library of more than 200 quality standards and a unified set of indicators designed to help define and measure quality in healthcare, public health, and social care. https://www.nice.org.uk/what-nice-does/standards-and-indicators **NICE Prostate Cancer Quality Standard (QS91).** Specific quality standard for prostate cancer care https://www.nice.org.uk/guidance/qs91
	SMRC Tools. Self-Management Resource Center California Offers a wide range of validated questionnaires used to measure outcomes in health education and self-management programs. https://selfmanagementresource.com/resources/evaluation-tools/
	M-PHOL Results & publications This section brings together EVPOP outputs on national health literacy policies and policy-related action. It provides practical resources to support countries in developing, implementing and strengthening health literacy

Categories	Theme: Evaluation and Research
	policies and supportive environments, and it documents shared learning within the M-POHL network. https://m-pohl.net/ResultsEVPOP
	EUROPROMS (Europa Uomo Patient Reported Outcome Study) STUDY is the first ever prostate cancer quality of life survey conducted by patients for patients. Design, setting, and participants: A cross-sectional survey was conducted among PCa patients currently receiving or having received treatment**.** https://www.europa-uomo.org/who-we-are/quality-of-life-2/the-euproms-study/
Gaps and Challenges	Difficulty in evaluating the credibility of online health information.
	Limited measurement tools, often focused only on reading and comprehension rather than decision-making.
	Lack of clear indicators for monitoring and evaluation.
	Scarcity of longitudinal studies.
	Difficulty measuring the real impact on health outcomes and equity.
Recommendations	Evaluation should not be limited to the level of knowledge, but should also measure the **real capacity to understand, decide and act**. Research should therefore focus on practical understanding, impact on quality of life, and the capacity to reduce inequalities, especially among vulnerable groups. Evaluation should include indicators such as: ● comprehension ● informed choice ● patient experience measures and patient-reported outcomes (PREMs and PROMs) ● decisional conflict With data disaggregated for vulnerable populations. It is also proposed to develop indicators that assess health systems not only by clinical outcomes but also by **the degree to which people understand the information they receive**, including diagnostic and therapeutic options and the processes related to their condition. Additionally, it is recommended to measure the impact of health literacy on **public expenditure**, including potential effects such as reduced emergency service use and better treatment adherence.
	Investment in **applied research** is needed to analyse which formats, messages, and environments best facilitate understanding and decision-making, considering face-to-face, digital, and community-based approaches.

Categories	Theme: Evaluation and Research
	Such research should involve patients and citizens in the design and evaluation of interventions and include the use of interactive virtual programs and the evaluation of their effective reach. Existing resources include evaluation tools from **self-management and health literacy programs** that measure the reach and effectiveness of interventions. There is also a need to establish **official websites providing curated lists of reliable sources** according to specific topics so that citizens have clear references for accessing trustworthy information.
	It is essential that the value of health literacy be made explicit and that **national strategies and action plans** be developed, including regular monitoring of population health literacy levels. For proper evaluation, it is necessary to: ● analyse the impact of campaigns ● use validated European indicators to measure health literacy ● estimate the return on investment of health literacy programs to adjust interventions when necessary. It is also recommended to promote research on **biomarkers** as part of the prostate cancer research agenda.
Resources and Links	https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/ https://www.nice.org.uk/guidance/qs91 https://www.nice.org.uk/what-nice-does/standards-and-indicators https://academic.oup.com/eurpub/article/35/Supplement_4/ckaf161.267/8303201?login=false https://pubmed.ncbi.nlm.nih.gov/33352951/ https://www.hphnet.org/wp-content/uploads/2021/08/SAT-OHL-Hos-v1-0-EN-international_update1.1.pdf https://selfmanagementresource.com/resources/evaluation-tools/ https://www.krebshilfe.de/informieren/ueber-krebs/ https://zenodo.org/records/11395540 https://www.europa-uomo.org/who-we-are/quality-of-life-2/the-euproms-study/

3.3. Analysis of the information collected from the in-depth interviews

Report on Key Informant Profiles (Context and Experience)

Between 18 February and 9 March 2026, a series of seven in-depth interviews were conducted to gather qualitative insights relevant to the study. The interviewees represented a diverse set of professional backgrounds, including three participants from universities or research centres, two from non-governmental organisations or

associations, and two from public administrations. In addition, the panel consisted of high-level experts from Spain, Romania, Portugal, and Switzerland, bringing together a multidisciplinary perspective on health literacy (HL), oncology, and patient advocacy.

The interviewees occupy strategic roles across the healthcare, research, and public health landscape, bringing together a rich combination of expertise and practical experience. Their professional backgrounds span patient advocacy, clinical practice, academic research, public health communication, and health literacy leadership. This combination of professional diversity and international expertise provides a robust and multidimensional foundation for understanding the issues explored throughout the interviews.

Their areas of experience reflect decades of work with diverse methodologies and innovative approaches in the health and social sectors. Several of the interviewees have extensive expertise in adapting and validating tools for clinical decision-making and quality-of-life assessment, including instruments such as the EPIC index for prostate cancer. Others have led national health literacy monitoring efforts, conducting both general and digital HL surveys among adult and adolescent populations. Qualitative research also plays a central role in their work, particularly through the systematic use of patient narratives to train healthcare professionals and support peer learning among patients. Additionally, many have pioneered new forms of health education by creating television programmes, podcasts, virtual classrooms, and large-scale patient congresses designed to enhance public engagement and improve access to reliable information.

Through their respective roles, these experts interact with a wide range of groups and communities. Their work often centres on patients and families managing chronic illnesses and cancer, with special attention to caregivers who frequently act as facilitators in the process of understanding and navigating healthcare information. Several initiatives specifically address the needs of vulnerable populations, such as individuals living in rural settings or those with medium-to-low educational attainment, who may experience greater barriers to accessing and interpreting health information. While much of their activity naturally focuses on older adults—given the higher prevalence of chronic disease

and cancer in this age group—some programmes are expressly designed for adolescents and young adults, particularly in the context of primary prevention. The interviewees also highlighted gender patterns in participation, noting that women tend to be more actively involved in health literacy initiatives, sometimes at ratios of seven to three, even when addressing male-specific health issues, due in part to their central role in managing family health responsibilities.

The main findings from the in-depth interviews are presented below.

3.3.1. Tools and strategies for health literacy

The experts identified a wide range of initiatives, ranging from institutional national strategies to innovative grassroots communication projects. A recurring theme is the lack of specific resources for prostate cancer compared to other pathologies like breast cancer or general chronic diseases. The resources specifically identified during the in-depth interviews are listed below, following two classifications to facilitate their use: Based on the care phase and in relation to the target audience.

Classification by stage of care

This classification follows the cancer continuum, from healthy individuals to those in advanced stages of the disease.

- **Prevention (Primary Prevention and Awareness):** This stage involves educating the public on modifiable risk factors (such as smoking, alcohol, and diet) to lower the overall risk of developing cancer. Successful interventions often use narrative-based communication and school-based programs to instil healthy habits from a young age.
    - **"Two Life Changing Minutes" (Portugal):** A fictional TV series used to teach healthy habits and cancer prevention. https://2minutos.pt/
    - **National HPV Vaccination and Education Program (Romania):** A multi-channel campaign involving TV, social media, and General Practitioners.

- **BUMPER Project / European Cancer Prevention App:** A digital tool based on the European Code Against Cancer guidelines. https://bumper.cancer.eu/
- **Movember / Social Media Awareness:** Grassroots initiatives using Instagram, podcasts, and merchandise (like themed T-shirts) to make prostate health visible. https://es.movember.com/
- **Sierra Nevada Climb:** A community initiative where patients climb mountains to raise awareness and normalize life after a diagnosis.
- **Swiss Cancer League Prevention Programs:** Broad awareness and advocacy work to support cancer prevention research and outreach. https://www.krebsliga.ch/

– **Diagnosis (Screening and Early Detection):** Health literacy during diagnosis centers on screening and early detection. A major priority is deconstructing myths—such as those surrounding the PSA test—and ensuring that patients understand the purpose and implications of diagnostic tests to make informed choices about entering care.

- **Workplace Screening Campaigns (Romania):** Bringing PSA and other blood tests directly to factories and large companies to increase participation.
- **InfoCure:** A Bertelsmann Foundation project is developing a certification process for medical information providers to ensure that patients find reliable data when seeking a diagnosis. https://www.bertelsmann-stiftung.de/de/startseite
- **HLS-19 (Ample/WHO Network):** National monitoring tools used in Switzerland and internationally to measure health literacy levels in the population. https://m-pohl.net/HLS19

- **Ophelia Process:** A participatory methodology used to identify community needs and develop localized screening and detection interventions. https://healthliteracydevelopment.com/

– **Treatment and Support:** This is a critical juncture where patients must navigate complex clinical options, such as the choice between radical surgery and active surveillance. Tools focus on shared decision-making and the use of "patient-reported outcome measures" (PROMs) to monitor and manage treatment-related side effects.

- **CLEAR-PC Project:** By the end of the project, CLEARP-PC aims to design and develop a comprehensive European strategy integrating user-centered health literacy resources for prostate care. https://clearpc.eu/
- **Canadian Shared Decision-Making Guide:** A specific tool adapted for Spanish patients to help them choose between treatments like surgery or active surveillance. https://decisionaid.ohri.ca/decguide.html
- **Expanded Prostate Cancer Index Composite (EPIC):** The global "gold standard" instrument used by researchers and clinicians to measure urinary and sexual side effects post-treatment.
- **Patient Schools (Andalusia and Basque Country):** Institutions providing "Aulas Abiertas" (open classrooms), virtual workshops, and "training of trainers". https://www.easp.es/
- **DIPEX / Health Experiences Database:** A collection of 16 countries' worth of patient narratives to provide emotional and practical support. https://www.dipex.es/nueva/
- **Musa Experience:** An initiative that transforms clinical data into artistic animation and documentaries to help patients assimilate complex information. https://www.musaexperience.com/

- **"Datos por Salud" (POP):** A project focused on educating chronic patients on how to manage and protect their digital health data. https://www.datospopsalud.org/
- **Patient Congresses:** Large-scale events attracting hundreds of patients to learn from peers and professionals.

- **Palliative Care:** In the advanced stages of the disease, the focus shifts to quality of life and specialized support for both patients and their families. Literacy efforts here use patient narratives and shared experiences to help individuals navigate the complex emotional and medical realities of end-of-life care.
  - **DIPEX Palliative Care Module:** A specific section of the database containing narratives from patients and families in advanced disease stages. https://www.dipex.es/nueva/cuidados_paliativos/
  - **Palliative Professional Training:** Specialized workshops for healthcare staff to improve communication in end-of-life care.

Classification by target audience

This classification identifies which agents are the primary recipients or users of these tools.

- **General Population (Citizens):** The primary goal for this group is primary prevention and raising awareness among healthy individuals before they enter the healthcare system. Strategies here focus on broad guidelines, such as the European Code Against Cancer, and use "edutainment" or mass media to compete for attention in the digital space.
  - **Interactive Web Platforms:** Tools like PyDeSalud (Spain) promote citizen participation in health care. In Switzerland and Austria, comprehensive HL platforms provide toolboxes and educational materials for the general public. https://pydesalud.com/

- **TV and Radio Programs:** Expert-led weekly health shows and podcasts aimed at broad public education and mass media tools designed to reach people before they become patients. For example, "For your health" from the afternoon program on Canal Sur Radio. https://www.canalsur.es/radio/programas/por-tu-salud/detalle/95.html?video=2177099 or "Two Life Changing Minutes" https://2minutos.pt/
- **Spanish Network for Health Literacy:** A group of professionals working to improve the general health system's communication pillars. https://www.alfabetizacionsalud.com/en/
- **Workplace Screening:** Innovative strategies in Romania involve collaborations with large companies and factories to offer blood tests (such as PSA for prostate cancer) and health education through internal HR and medical offices.
- **National Awareness Campaigns:** Broad campaigns via national TV and social media are used for primary prevention (e.g., HPV vaccination in Romania and cancer prevention series in Portugal).

– **Patients and Families/Caregivers:** This category focuses on those directly affected by a diagnosis. Families and caregivers are essential because they often act as "intermediaries," especially for elderly patients with lower digital skills. Resources for this group emphasize shared decision-making, peer support, and managing the emotional and practical burden of the disease.

- **Patient Education Schools:** The "School of Patients" (Andalusia) and "Osasun Eskola" (Basque Country) and the Andalusian School of Patients, which offer workshops, "Open Classrooms," and peer-to-peer training. https://www.easp.es/; https://osasuneskola.osakidetza.eus/es/catalogue/paciente-activo
- **GuiaSalud.es:** A repository of clinical practice guidelines adapted for patients and their relatives. https://portal.guiasalud.es/

- **Patient Organizations:** Groups like the POP (Spain) and the National Association of Prostate Cancer (ANCAP) provide materials and act as a bridge to health information. https://plataformadepacientes.org/ https://ancap.es/
- **Sierra Nevada Climb & Peer Networks:** Grassroots support systems for men with prostate cancer.
- **Decision-Making Tools:** Specific decision aids (often adapted from international models like Canadian guides and the EPIC index used directly by the patient) help them choose between treatments for localized prostate cancer. https://obsaludasturias.com/obsa/category/epic/

– **Healthcare Professionals:** Professionals, including GPs, urologists, and nurses, are the most trusted sources of information. The focus here is on "prescribing information," improving organizational health literacy, and training clinicians to better support patients in navigating digital health resources and addressing their fears.

- **Point of Care (POC) Channels:** Digital channels used to provide information to patients directly during clinical consultations.
- **Careum Centre / Organizational HL Tools:** Research-based tools to help clinics and hospitals improve their institutional communication. https://careum.ch/en
- **Professional Digital Health Literacy (DHL) Measurements:** Tools used in Switzerland, Austria, and Germany to evaluate how well staff can support patients' digital needs.
- **Education and Training:** Narratives from databases like DIPEX are used as educational material for medical students to help them understand the patient's perspective. https://www.dipex.es/nueva/

– **Policy Makers:** To drive systemic change, this group requires evidence based on economic viability and national indicators. Strategies involve advocating for free

screening, regulating the quality of digital health information, and creating a legal and organizational environment that fosters better literacy at a national level.

- **Economic Evaluation**: Projects like Preventable develop videos and materials to show, by patient stories and economic data, policymakers that prevention and early detection are more economically viable than late-stage treatment. https://preventable.eu/
- **Policy Guides:** Specific policy guides and monitoring reports (like the HLS-19) are used to inform national health literacy strategies. https://m-pohl.net/HLS19
- **Digital Health Strategy (Spanish National Health System):** The institutional framework governing the digitalization of health resources. https://www.sanidad.gob.es/areas/saludDigital/doc/Avances_de_la_Estrategia_de_Salud_Digital_web.pdf

3.3.2. Successful initiatives and transferability

The interviewed experts have identified several initiatives or programmes that they consider particularly relevant due to their reach. Below, we present the reasons why they regard these initiatives as successful, as well as their potential for transferability.

Prevention (Primary Prevention and Awareness)

- **Edutainment: "Two Life Changing Minutes" (Portugal)**
  - **Scale:** National.
  - **Reason for Success:** It uses a fictional narrative format (television series) with real actors during prime-time TV to convey prevention messages (smoking, alcohol, etc.) in a digestible, non-clinical way.
  - **Exportability:** High; the content was adapted into an online course for teachers to use in classrooms with students.
  - **Impact:** Peer-reviewed papers showed that viewers who emotionally engaged with the narrative demonstrated greater behavior change compared to control groups.

- **Workplace Screening Programs (Romania)**
  - **Scale:** Local/Regional.
  - **Reason for Success:** Partnering with large factories and companies to offer blood tests (such as PSA or gastric screening) at the workplace. This overcomes the barrier of time and access for the working-age population.
  - **Exportability:** Highly exportable to any industrial or corporate environment.
  - **Impact:** Observed a high participation rate because employees can easily attend during work hours.
- **National Awareness Campaigns (Romania - HPV Model)**
  - **Scale:** National.
  - **Reason for Success:** Combining mass media (TV/Social Media) with the active participation of General Practitioners (GPs), who handle the direct communication and prescription.

2. Diagnosis (Screening and Early Detection)

- **Normalization through Visibility (Breast Cancer Benchmark - Spain/Portugal)**
  - **Scale:** National.
  - **Reason for Success:** While focused on breast cancer, experts cite this as the "gold standard" for prostate cancer to follow. Its success is rooted in the normalization of screening (mammograms) and high social visibility.
  - **Exportability:** The "visibility" strategy is being adapted to prostate cancer by initiatives like "Movember" or "Speak about the Prostate" to break taboos.
- **Organizational Health Literacy Tools (Switzerland/Global)**
  - **Scale:** Global (Ample/WHO network).

- **Reason for Success:** A self-assessment tool for primary care settings to improve how they communicate diagnosis information to patients.
- **Exportability:** Fully internationalized and available via the Ample network.

3. Treatment (Shared Decision-Making and Support)

- **Shared Decision-Making (SDM) Guides (Spain/Canada)**
  - **Scale:** National/International adaptation.
  - **Reason for Success:** Adaptation of the Canadian SDM guide for localized prostate cancer. It helps patients understand that surgery (prostatectomy) is not the only option, introducing "active surveillance" as a valid path.
  - **Exportability:** Already adapted from Canadian to Spanish contexts; exportable to any healthcare system where treatment options are varied.
- **"Escuela de Pacientes" (Andalusian School of Patients, Spain)**
  - **Scale:** Regional with National impact.
  - **Reason for Success:** Uses peer-to-peer training, podcasts, and "Virtual Classrooms" where experienced patients train newly diagnosed ones, fostering emotional and practical literacy.
  - **Impact:** Host Patient Congresses attracting 400-500 participants, leading to measurable improvements in the professional-patient relationship.
- **EPIC Quality of Life Index (Global)**
  - **Scale:** Global standard adapted to Spain.
  - **Reason for Success:** Validated tool (Patient Reported Outcome Measure) that allows patients to communicate side effects (urinary, sexual) to doctors effectively.

4. Palliative Care and Long-term Support

- **DPEX / Health Experiences (International/Spain)**
  - **Scale:** Global (16 countries).

- **Reason for Success:** A database of individual patient narratives. It is successful because it provides "reliable identification"—patients see others who have survived or managed advanced stages, which reduces isolation.
- **Exportability:** Part of an international collaboration; narratives are systematically collected using the same methodology across different cultures.
- **Impact:** Used in medical education (undergrad/postgrad) to train future doctors on the emotional realities of palliative care.

- **"Sierra Nevada Climb" (Granada, Spain)**
  - **Scale:** Local.
  - **Reason for Success:** An awareness-raising event where patients with prostate cancer climb a mountain. It builds community support and demonstrates that a cancer diagnosis is not an end to an active life.

3.3.3. Platforms and formats used

The interviews conducted across various European contexts highlight a significant transition toward digital formats, although traditional methods remain essential for ensuring accessibility for older populations and those with lower digital literacy.

- **Digital Platforms.** At the institutional level, health information is predominantly hosted on static websites and massive open online courses (MOOCs), such as the integrated services offered by PID de Salud or specific qualitative research training modules. While mobile applications are frequently developed to target younger adults, experts warn that maintaining long-term engagement is extremely difficult because these tools must compete for space and attention on smartphones against highly addictive social media platforms. Consequently, social media tools like Instagram and WhatsApp are emerging as more effective channels for "equal-to-equal" communication, allowing for the rapid dissemination of "health pills" that fit into the daily digital routines of users.

- **Audiovisual and "Edutainment".** To increase emotional engagement, many initiatives now utilize audiovisual formats, including podcasts and video chats, which serve as platforms for sharing patient testimonies and professional interviews. A prominent example of successful "edutainment" (educational entertainment) is a fictional TV series produced in Portugal, where short five-minute episodes are broadcast during prime time to teach cancer prevention through compelling narratives rather than clinical lectures. Additionally, innovative strategies like the Musa Experience involve the artistic transformation of scientific results into animation videos, which help make complex medical data more digestible and affectively resonant for the audience.

- **Traditional Formats.** Despite the rise of digital tools, traditional formats such as written guides and brochures remain the most common resources provided by patient organizations and health centers, even though some experts now view them as somewhat "old-fashioned". In contrast, infographics continue to be highly valued across all demographics for their unique ability to present the most relevant health information clearly while strictly avoiding the technical jargon that often creates barriers to understanding.

3.3.4. Gaps and challenges

The analysis of gaps and challenges in health literacy (HL) reveals that vulnerable groups, particularly the elderly and those in rural or disadvantaged environments, face significant barriers due to a pronounced digital divide.

Experts emphasize that while the population is aging, chronic diseases are becoming more prevalent, yet there is a notable lack of specific, unified information regarding prostate cancer compared to other pathologies. This information gap is exacerbated in rural areas where the educational profile is often medium-low, leading patients to rely heavily on associations because they cannot find clear pathways in standard clinical practice.

For men over 40, a major hurdle is the lack of proactive health engagement; data suggests they often do not connect with the healthcare system until a problem arises, unlike

women who are generally more proactive in seeking health information. Furthermore, in some vulnerable communities, such as the Roma population, there is such a fundamental lack of health literacy that some individuals may not even know what the prostate is or its physiological role.

A critical challenge for those with low digital skills is that most modern health content is hosted exclusively online, which effectively excludes many older patients or forces them to rely on "intermediaries" like family members. This reliance creates a new vulnerability, as the intermediary's interpretation or criteria may override the patient's own preferences.

Additionally, there is an emerging need for "data literacy," as patients must now learn not only about their disease but also how to manage, govern, and interpret data from digital devices and technological innovations within the national health systems. Even for those who are digitally active, engagement is difficult because health resources must compete for attention on smartphones against highly addictive platforms like TikTok or Instagram.

Regarding message adaptation, experts agree that current materials are often not sufficiently tailored to different educational levels or cultural contexts. There is a strong call to move away from technical jargon and 60-page clinical guides, which assume a level of medical knowledge that most patients do not possess. Instead, the need is for "educational pills", short videos, and dynamic infographics that are visually accessible and easy to digest. Cultural and gender taboos also play a major role; the prostate is often treated as a "hidden" organ that is not talked about, which prevents the normalization of check-ups like the digital rectal exam. This "silence" around male health contrasts sharply with the high visibility and social normalization of breast cancer screening for women.

Finally, trust remains a complex issue influenced by the source and format of information. While patients generally maintain high trust in their General Practitioners (GPs) and social workers, they are increasingly exposed to dangerous misinformation in social media forums where fears are shared without scientific oversight.

The rise of Artificial Intelligence and chatbots presents a new risk, as many users—especially younger ones who may lack a "critical spirit"—might use these tools as "digital psychologists" without being able to distinguish reliable evidence from hallucinations or

"fake news". To combat this, experts suggest that healthcare professionals must transition toward "prescribing information," directing patients to certified, reliable digital sources during consultations to ensure that the information found online reinforces rather than undermines clinical care.

3.3.5. Key agents and strategic roles in health literacy

Improving health literacy in prostate cancer care requires a multifaceted approach where healthcare professionals act as the primary trusted sources. General Practitioners (GPs) and nurses are essential because they maintain long-term relationships with chronic patients, making them the ideal agents to "prescribe" reliable digital information during consultations. Within the specialized field, urologists and radiation oncologists serve as the technical entry points for diagnosis and treatment; however, their impact is maximized when they collaborate with primary care to provide a continuous and unified educational message to the patient.

A central pillar of this strategy is the active involvement of patient organizations and peer-support networks, which act as a vital nexus between the clinical world and the patient's daily life. These groups are indispensable because they fill gaps in the formal healthcare system by providing emotional support, reducing isolation, and offering "lived experience" that helps patients identify with others in similar situations.

- Specifically, the "expert patient" is a crucial profile for future initiatives; these individuals can act as trainers for the newly diagnosed, providing practical and relatable perspectives that professional clinical staff may not be able to convey.
- Furthermore, caregivers and families are identified as critical stakeholders, particularly for patients over 60 or those in rural areas. Since these patients often have low digital skills, their relatives act as "intermediaries" who perform searches and navigate health apps, making the family's health literacy a direct factor in the patient's own care outcomes.

To increase impact, strategic alliances must be forged across sectors. Collaborations between scientific societies and patient associations are necessary to ensure that educational materials are both medically accurate and linguistically accessible. On a

structural level, policymakers and government bodies must provide the regulatory framework and funding for national awareness campaigns and screening programs, ensuring that diagnostic tools like PSA tests are accompanied by the necessary literacy resources.

Finally, media and technology companies contribute by amplifying health messages through innovative formats. "Edutainment" strategies, such as fictional TV series, podcasts, and social media campaigns involving celebrities or sports figures, can normalize the conversation around prostate health and reach healthy individuals before they become patients.

For digital innovations—such as Artificial Intelligence and chatbots—to be effective and safe, technology providers must collaborate with health experts to integrate quality indicators into their algorithms. This ensures that users are directed toward certified information, protecting them from the misinformation prevalent in uncontrolled digital forums. Ultimately, this ecosystem only succeeds if the patient is included as a co-creator from the design phase, ensuring that all tools and strategies respond to real-world needs.

3.3.6. Future lines

The future of digital health literacy ((d)HL) in prostate cancer care depends on shifting from merely providing information to creating a regulated, evaluative, and patient-centered ecosystem. Experts emphasize that the coming years must prioritize research into the evaluation of interventions, as much of the current work involves "reinventing the wheel" without verifying what actually works. There is a critical need for qualitative evidence that measures the perceived impact and subsequent behavior changes—such as treatment choices or screening uptake—rather than relying on superficial metrics like website visits or document downloads.

Key research and action priorities include:

- **Involving patients as co-creators** from the design phase of studies and educational tools to ensure they address real emotional and practical needs before resources are fully developed.

- **Developing "Critical Health Literacy"**, specifically teaching the population—especially younger generations—how to distinguish between reliable evidence and dangerous misinformation or "fake news".
- **Organizational Health Literacy**, which moves the focus away from individual patient responsibility and toward changing how healthcare organizations and professionals are structured to support information exchange.

Technological innovations considered most valuable are those that bridge the gap between clinical data and patient understanding. Artificial Intelligence (AI) and chatbots are seen as high-potential tools for 24/7 support, provided they are built on certified data and users are taught "prompting" as a new digital health skill. Another significant innovation is the "prescription of information," where digital systems (like electronic medical records) automatically suggest or send certified, filtered links to reliable websites directly to the patient during their clinical journey. AI is also suggested as a tool for visualizing complex medical concepts, such as the physiological role of the prostate or the physical impact of a tumor, to make technical information digestible.

At the policy and investment level, experts call for a massive increase in funding for communication. Currently, excessive energy is spent on building tools, while only a small fraction (around 5%) is spent on reaching the target audience, rendering many high-quality resources invisible. Furthermore, there is a push for:

- **National certification systems** for health information providers to ensure that social media algorithms prioritize trustworthy, evidence-based content.
- **Investment in free screening methods** (such as PSA tests) and rapid testing within primary care to reduce economic barriers to diagnosis.
- **Training for health professionals** so they are equipped to guide patients through the digital landscape and handle queries arising from internet searches.

Regarding current strategies, experts advocate for specific shifts in how health literacy is approached:

- **Adopt:** "Edutainment" (educational entertainment) such as fictional TV series and podcasts to engage healthy populations, and the "prescription of information" as a standard clinical practice.
- **Maintain:** Peer-to-peer support networks and "expert patient" programs, as the testimony of an equal remains a powerful driver for behavior change. National monitoring of health literacy levels should also continue to track progress.
- **Change:** Move away from long, technical, 60-page clinical guides and "old-fashioned" paper brochures. Instead, the strategy should focus on "educational pills"—short videos, dynamic infographics, and interactive content—that avoid technical jargon and respect the short attention spans of modern digital users.

3.3.7. Other relevant aspects to consider

Based on the expert interviews conducted as part of the CLEAR-PC project, several specific nuances and innovative approaches have also been identified that provide a broader understanding of the challenges and opportunities in digital and non-digital health literacy ((d)HL).

1. Health Literacy in Adolescents and Young Adults. While prostate cancer primarily affects older men, experts emphasize that the foundation for long-term prevention is laid in youth. Innovative research is currently being conducted in countries such as Switzerland, to measure and improve the HL levels of adolescents aged 14 to 17. This approach involves developing specific instruments to measure digital health literacy with the direct participation of young people, ensuring that future generations are better equipped to navigate the complex digital health ecosystem and manage cancer risks later in life.

2. Economic Viability as a Strategic Tool for Policy Makers. A crucial aspect of advocacy involves translating clinical benefits into economic arguments. Projects like the European initiative Preventable aim to demonstrate to health managers and politicians that prevention and early detection are more economically viable for hospitals than treating advanced-stage cancer. Experts suggest that providing data-driven facts

regarding the costs of treatment versus the costs of prophylactic surgery or screening is often more persuasive to decision-makers than clinical narratives alone.

3. Institutional Fragmentation and the Need for Unified Criteria. In countries like Spain, a significant challenge is the lack of coordination between regional health systems. Research indicates that "Health Schools" vary wildly across autonomous communities; for instance, some regions certify training in up to 16 different pathologies, while others cover only four or five. This fragmentation leads to a "waste of resources" where high-quality materials developed by patient organizations are not fully utilized or integrated by public health institutions.

4. Artistic Transformation and Affective Impact. To overcome the limitations of traditional brochures and technical guides, experts propose the artistic transformation of scientific data. Initiatives like Musa Experience convert research findings into animations, short films, or documentaries. The goal is to produce an "affective impact"—moving the patient emotionally rather than just intellectually—since emotional connection is often a more powerful driver of behavior change than simply reading a set of instructions.

5. The Dilemma of "Indolent Cancer" and Active Surveillance. Prostate cancer presents a unique communication challenge: the concept of "active surveillance" for indolent (slow-growing) tumors. It is often difficult for patients to understand why "doing nothing" is a valid medical option when their social and psychological expectation is that a cancer diagnosis requires aggressive intervention like surgery or radiation. Literacy efforts must specifically address the side effects (urinary and sexual) of treatments to help patients weigh quality of life against the risks of unnecessary intervention.

6. From Individual to Organizational Health Literacy. There is a growing shift from focusing solely on the patient's skills to analyzing "Organizational Health Literacy" (OHL). This involves evaluating how healthcare organizations—especially primary care settings—are structured to facilitate or hinder access to information. It also includes measuring "Professional Digital Health Literacy," which is the ability of clinicians to support their patients in managing digital health information and tools.

7. The "Homer Simpson Effect". A recurring issue in clinical practice is the gap between a professional's perception of patient understanding and reality, colloquially referred to as the "Homer Simpson Effect". This term refers to a famous scene where Homer is asked if he understands how a polygraph works; he replies "Yes," and the machine immediately explodes. In health literacy, this illustrates the danger of professionals presupposing that a patient understands simply because they nod or download a document. Experts argue that literacy is not about the consumption of information but about the interpretation and assimilation of it, which often differs radically from the clinician's intention.

3.3.8. Other questions that experts highlighted

How is edutainment used to raise cancer awareness?

Educational entertainment (edutainment) is used as a strategic tool to reach people who are not currently ill but need information on prevention.

- **Narrative Engagement:** Instead of traditional clinical brochures, experts use fictional television series with real actors and scripts. These narratives create emotional connections, and studies show that the more viewers engage with the story, the more they are likely to change their health behaviors.
- **Mass Media Reach:** Short, 5-minute episodes are broadcast during prime time (e.g., in Portugal) to ensure maximum visibility among the general population.
- **Thematic Focus:** Each episode can focus on a specific risk factor—such as smoking, alcohol, or sun exposure—to make the information digestible and relevant.
- **Multimedia Integration:** These materials are often repurposed into online courses for teachers to use in classrooms, extending the reach to younger generations.

What specific digital barriers do patients over 60 face?

Patients over 60 face several critical barriers in the modern digital health landscape:

- **The Digital Gap:** While younger generations are technology-native, many elderly patients struggle to use the digital platforms (websites, apps) where most modern health resources are now hosted.
- **Reliance on Intermediaries:** Many older patients do not use the internet directly and depend on family members or caregivers to find and interpret health information for them. This can lead to the patient's own criteria being overshadowed by the intermediary's interpretation.
- **Lack of Training:** There is a significant lack of specific training for older adults on how to navigate social networks or use digital health tools effectively and safely.
- **Rural Isolation:** In rural environments, older populations may lack both the hardware (smartphones/computers) and the connectivity needed to access digital awareness campaigns, making them reliant solely on their General Practitioner (GP).

What is the Role of Families in Digital Health Literacy?

Families and caregivers are fundamental pillars in the health literacy process, especially when dealing with elderly patients or those with low digital skills. Their role can be summarized into the following key points:

- **Acting as Digital Intermediaries:** For patients over the age of 60 or those living in rural areas, family members often serve as the primary "bridge" to digital information. These "intermediaries" are the ones who actually perform internet searches, navigate apps, or use social media on behalf of the patient.
- **A Source of Vulnerability:** While families provide access, this intermediation can create a point of vulnerability. Experts note that sometimes the intermediary's criteria may override the patient's own preferences or interpretation of the information.
- **Support in Chronic Care:** In chronic pathologies, such as diabetes or cancer, the partner (often the wife) plays a central role in daily care and management. This is so prevalent that researchers often have to specifically seek out men who live

alone to find narratives that do not involve a partner's management of the disease.

- **Target of Educational Resources:** Because the family is also "affected" by the diagnosis, many health literacy initiatives (such as the *Guía Salud* or the Andalusian School of Patients) specifically design their materials to include caregivers and relatives.

How gender influences information seeking

Gender is one of the most significant factors influencing how health information is sought and consumed. The sources highlight several distinct patterns:

- **Higher Female Proactivity:** There is a clear "feminine bias" in health engagement. Women are significantly more likely to participate in health literacy workshops, seek out information, and join patient associations. Experts report a consistent participation ratio of 7:3 or even 7.5:2.5 in favor of women.
- **Women as "Health Managers":** Even when the topic is male-specific, such as prostate cancer, women (wives or daughters) are often more engaged with the content than the men themselves. They act as the primary seekers of information for their husbands, who may be less inclined to investigate their own condition.
- **Cultural Normalization and Taboos:** Gender also influences what is "visible" in health. While procedures like mammograms for breast cancer are highly normalized among women, men often face a lack of awareness or even rejection toward prostate-related checkups, such as the digital rectal exam.
- **Communication Styles:** Men tend to talk less about their health issues, which "hides" the disease. Experts emphasize that for men, the strategy must focus on "making the prostate visible" and encouraging them to speak openly, as what is not talked about "does not exist"

4. CONCLUSIONS

The methodology employed in the CLEAR-PC project—combining a broad initial survey with in-depth interviews—proved essential for capturing both the diversity of stakeholders' experiences and the contextual nuances that shape digital and non-digital health literacy in prostate cancer. The brief survey enabled wide participation across countries and professional backgrounds, ensuring representativeness and helping identify individuals willing to contribute further. The comprehensive interviews then deepened the understanding of lived realities, systemic barriers, and unmet needs, while the use of digital tools such as Microsoft Teams and automated transcription supported accuracy and consistency across data sources. The co-designed process used to build the stakeholder matrix added another layer of methodological robustness, applying evidence-based frameworks and collective validation to ensure coherence across work packages. Altogether, this triangulated approach strengthened the reliability of findings and supported a multidimensional analysis that reflects patient, professional, organisational, and policy-level perspectives.

Across the different inputs, a rich constellation of actors emerges, ranging from international bodies such as WHO or OECD to national administrations, patient organisations, academic groups, civil society, and private-sector innovators. These actors participate in the production of resources, dissemination of information, and the creation of educational materials and support services relevant to health literacy and prostate cancer. However, their contributions often exist in fragmented silos and vary greatly between territories, resulting in duplication of efforts and discontinuity. Even within Europe, networks are insufficiently connected to community structures, the education sector, or primary care—despite the latter being repeatedly highlighted as the most strategic point for contextualised, equitable information delivery. Patient associations stand out as indispensable intermediaries that translate evidence into accessible formats and foster engagement, but their involvement is not systematically integrated into national or regional health strategies.

Interview and survey data confirm that major gaps persist despite the abundance of general health literacy resources. A paradox emerges: while generic health information is plentiful, specialised resources addressing the complexity of prostate cancer remain scarce, poorly adapted, or difficult to navigate. This scarcity is further exacerbated by taboos surrounding men's health, which suppress discussion, delay help-seeking, and reinforce inequalities. Digital health literacy gaps mirror broader social and digital divides: older men, in particular, frequently depend on partners, children, or caregivers who act as "digital intermediaries", sometimes filtering or interpreting information in ways that unintentionally override patient autonomy. Problems of poorly designed messaging, over-complex language, the rapid spread of misinformation in social media, and absence of user-centred digital tools also contribute to limited comprehension and decisional uncertainty.

Decision-making processes appear especially vulnerable to these gaps. While frameworks for shared decision-making exist, they are applied unevenly due to lack of time, insufficient training, and limited availability of validated, easy-to-understand decision aids. Clinicians, especially general practitioners and urologists, emerge as the most trusted guides in the patient journey and are the ones who can effectively "prescribe information" by directing patients to certified sources. Yet even this interaction is undermined by what experts call the "Homer Simpson effect": clinicians often assume understanding based on superficial cues, while patients may leave consultations with confused interpretations of risks, treatment options, or expected side effects. Interviews repeatedly emphasise that quality communication is not defined by the quantity of information but by whether people can understand, evaluate, and use it to act. This includes giving patients time to reflect, opportunities to ask questions, and materials adapted to their cultural, linguistic, and cognitive needs.

The theme of prostate cancer screening appears persistently throughout the data, even when not explicitly prompted. Experts describe a widespread discrepancy between public expectations and the scientific uncertainty surrounding population-wide screening: while PSA testing increases early detection, it does not consistently reduce mortality and carries risks of false positives, overdiagnosis, and overtreatment. This uncertainty translates into

highly heterogeneous practices across countries and even across clinics. The absence of clear management algorithms for opportunistic screening contributes to care overload and patient confusion. Informants call for transparent communication materials explaining risks and benefits, decision-support tools, risk calculators, and harmonised guidelines that reduce variability. They also highlight the need for research on biomarkers and risk stratification to refine personalised screening pathways.

Gender dynamics permeate nearly all findings. Experts consistently report that women are far more proactive in health management and often take responsibility for navigating information for male family members. This gendered pattern contributes to lower engagement among men, reinforcing the culture of silence around prostate health. The stigma and discomfort associated with discussing the prostate, masculinity, sexual function, or urological symptoms further limit men's participation in awareness activities. To counter this, informants recommend edutainment strategies—such as popular TV series or short, emotionally resonant "educational pills"—that normalise discussion, foster identification, and avoid technical jargon. These tools are seen as powerful ways to break taboos and promote preventive behaviours before symptoms arise.

Looking ahead, the insights collected point to clear priorities for future work. Co-creation must become standard practice, ensuring that patients, survivors, and their families participate from the outset in designing interventions, materials, and policies. Digital solutions such as AI-based assistants or chatbots hold potential for expanding access to reliable information, but they also require users to acquire new digital skills and a critical mindset to evaluate online content. Evaluation practices should evolve to measure not only knowledge but also understanding, engagement, decision quality, and long-term outcomes such as adherence and quality of life. Importantly, despite being part of the survey, palliative care received almost no attention from informants, which indicates a neglected area that should be explicitly addressed in the next phases of CLEAR-PC. Overall, the findings show that improving health literacy in prostate cancer requires a cultural shift, stronger integration of actors and networks, better-adapted tools, and rigorous evaluation of real-world impact, moving beyond information dissemination to

truly empowering people to make informed, confident decisions across the entire care pathway.

Closing sentence

We would like to thank all the people who responded to the general survey, as well as those who participated in the in-depth interviews, for generously sharing their knowledge and experience with the CLEAR-PC project.

5. ANNEXES

Annex 1. Focus group for the development a Stakeholder Matrix

Focus group for the development of a Stakeholder Matrix

Title: Design of the information collection sheet for the stakeholder list in the CLEAR-PC Project
Duration: 60 minutes
Participants: WP leaders + 1 moderator + 1 rapporteur
Format: online (Meet), with prior consent to record
Objective: To co-design and validate a methodology for developing a Stakeholder Matrix in research projects: application to the CLEAR_PC case study

1. Introduction and objectives (5 min)

- Welcome and outline the purpose: to review and finalise the structure of the Excel sheet.
- Get informed consent from all the participants.
- Remind participants that the goal is to achieve consistency, clarity, and usability across all WPs.
- Explain that the discussion will focus on three tabs: “Stakeholders,” “WP_Activities,” and “Info.”

Questions:

2. Review of “Stakeholders” sheet (20 min)

Description: this sheet is intended to register information about the stakeholders who will participate in the CLEAR-PC project.

Objective: ensure the variables accurately capture key actors and their involvement.

Questions:

- What is your opinion about the usability of this matrix?
- In your opinion, what added value do the columns in the green area provide in relation to the goals of this study?
- What other columns, if any, could be useful for this study?
- From your perspective, how does detailing each activity in which the stakeholders will be involved, including its name and timeline, in the grey area (columns J to U) enhance the purpose of this study?
- How do you perceive the pertinence of the columns in the blue area (from N to Q)?

3. Review of “WP_Activities” sheet (10 min)

Description: This sheet details the activities that stakeholders are expected to participate in.

Objective: align the activity table with the current planning and reporting needs.

Questions:

- In your opinion, what added value gives this sheet to the identification of the stakeholders that will be involved in the study?
- Are there any other types of information you believe would enhance the usefulness of this sheet?

4. Review of "Info" sheet (20 min)

Description: This sheet describes the items identified in certain columns of the 'Stakeholders' sheet, allowing for controlled input through drop-down menus.

Objective: verify the consistency of partner information and stakeholder expertise and category data.

Questions:

- Based on the activities the stakeholders will be involved in, which items do you consider relevant to include in the "stakeholder category" section to create the drop-down menu?
- Based on the activities stakeholders will be involved in, which items do you consider relevant to include in the "stakeholder areas of expertise" section to create the drop-down menu?
- Based on the activities stakeholders will be involved in, which items do you consider relevant to include in the "stakeholder role" section to create the drop-down menu?

Any other suggestion for the improvement of the Excel?

5. Summary and next steps (5 min)

- Summarise agreed changes and open issues.
- Next steps.

Annex 2. Key informants email model – General survey

Dear [Name / Organisation],

My name is (xxxxxxx). I am contacting you on behalf of the CLEAR-PC project (Cancer Literacy Education and Awareness Resources for Prostate Care), co-funded by the EU4Health Programme (GA nº 101219353) and implemented by 17 partners across Spain, Portugal, Croatia, Belgium, the Netherlands and Cyprus. CLEAR-PC aims to design, co-create and evaluate a European strategy to improve digital and non-digital health literacy related to PCa prevention, early diagnosis, treatment decision-making and palliative care.

We would like to kindly invite you to collaborate with the project by answering this very short questionnaire about health literacy. Link: Questionnaire CLEAR-PC: Health Literacy strategies and tools

The purpose of your participation in CLEAR-PC by answering this questionnaire is to collect expert insights and examples on existing tools, strategies, and practices in Europe and beyond to improve health literacy and digital health literacy, both related and unrelated to PCa.

The goal is to map the current state of the art, identifying gaps and best practices, and provide a knowledge base to guide the development of the CLEAR-PC strategy for improving communication, awareness, and patient engagement in PCa care.

It will take you less than 15 minutes to complete this questionnaire.

Your participation is voluntary and anonymous. A **certificate acknowledging your contribution** to CLEAR-PC will be issued upon request.

We would greatly appreciate it if you could send us your response by January 15, 2026.

Thank you very much in advance.

Annex 3. Key informants Email model – In-depth Interview

Dear [Name],

I am writing in relation to the survey you recently completed as part of the EU project **CLEAR-PC** (Cancer Literacy Education and Awareness Resources for Prostate Care https://clearpc.eu/). The survey was aimed to collect valuable insights from experts about strategies and methodologies in the field of health literacy and digital health literacy ((d)HL).

Given your extensive experience in this field and your willingness to participate in an in-depth interview, I would like to kindly invite you to a one-hour session aimed at gathering information on existing strategies, tools, and knowledge related to (d)HL, both in general and specifically beyond the context of prostate cancer.

The interview will take place via the Microsoft Teams platform. Would it be possible for you to schedule a one-hour slot on **xxxxxxxxxx, xx xxxxxxx, from xx:00h till xx:00h**?

If you accept the invitation, we will send you the informed consent form and the interview guide ahead of the meeting. The informed consent will be collected at the beginning of the interview, which will be recorded and transcribed for subsequent analysis. All information will be anonymised.

Do not hesitate to ask for any clarification.

Thank you very much in advance.

Annex 4. Short questionnaire for the general survey (provided by FORMS)

HEALTH LITERACY strategies, tools and information

Dear Expert,

Firstly, we would like to thank you for collaborating on the European project CLEAR-PC.

The **CLEAR-PC project - Cancer Literacy Education and Awareness Resources for Prostate Care**, is a project co-funded by the European Union under EU4Health Programme (GA nº 101219353) and implemented by 17 partners across Spain, Portugal, Croatia, Belgium, the Netherlands and Cyprus. CLEAR-PC aims to design, co-create and evaluate a European strategy to improve digital and non-digital health literacy related to prostate cancer prevention, early diagnosis, treatment decision-making and palliative care.

The purpose of your participation in this survey is to collect expert insights and examples on existing tools, strategies, and practices in Europe and beyond to improve health literacy and digital health literacy, both related and unrelated to prostate cancer.

The goal is to map the current state of the art, identifying gaps and best practices, and provide a knowledge base to guide the development of the CLEAR-PC strategy for improving communication, awareness, and patient engagement in prostate cancer care.

Your participation is voluntary and the answers are confidential.

Thank you very much for your participation.

It will take you less than 15 minutes to complete this questionnaire.

Information Regarding Data Protection and Confidentiality:

1) FICYT (Spain) is responsible for the processing of the data collected by this survey. Write to clear-pc@ficyt.es for any communication.

2) This survey is confidential, in full conformity with the EU General Data Protection Regulation (GDPR), as well as any additional applicable legislation. Your answers will not be shared outside the CLEAR-PC consortium, and they will be exclusively used for research purposes under the project.

3) No personally identifiable information will be collected, which would allow the identification of respondents.

4) The final conclusions will be shared within the CLEAR-PC countries and beyond in the framework of research activities.

1.To participate, select the corresponding option

Yes, I accept

No, I do not accept

2.Which type of organization does your entity belong to?

- Public administration
- University / Research centre
- Private sector
- Civil society organization (NGO, Association, etc.)
- Other

3.Please indicate the name of your organization.

QUESTIONS:

4.Existing tools and strategies.

Based on your experience, are you aware of any **tools, programs, or strategies** currently being used (in your region, country, or internationally) to promote health literacy? Are any of them applied in the field of cancer? Or specifically in prostate cancer? Please list them, summarise them, and add the link if possible.

5.Successful initiatives and examples.

Could you identify any **best practices** or successful initiatives on health literacy at **regional, national, or European level** that you believe could inspire or be adapted to the context of prostate cancer screening, treatment decision-making, and palliative care?

6.Gaps and challenges.

In your opinion, what are the main **gaps, challenges, or unmet needs** in relation to health literacy? Are you aware of any in general cancer care or even more specifically in prostate cancer?

7.Involvement of all stakeholders.

Which types of **population profiles** should participate more actively in improving health literacy on prostate cancer?

- Healthcare professionals
- Patients and their families
- General population
- Other

8.Could you suggest any **specific entity** that you know and that represents any of the above-mentioned profiles?

9.Future directions and research needs.

Based on your experience, what **future actions, evaluation and research priorities, or policy measures** would you recommend strengthening health literacy in Europe and globally?

10.Additional comments.

Is there any **additional comment, tool, or resource** you would like to share that could be useful for the CLEAR-PC project? (You may include links, references, or contact suggestions).

11.Meeting for short online interview.

Would you be willing to participate in an online interview to further explore your contributions to the field of health literacy and digital health literacy? You will be issued a certificate recognising your contribution to CLEAR-PC.

- Yes
- No

12. If yes, please provide your email address and we will contact you to arrange the interview.

13.Would you like to participate as an expert or stakeholder officially in the CLEAR-PC project? The CLEAR-PC project is developing an international network of stakeholders

in the field of health literacy on prostate cancer. Would you be interested in being included in this network? If you wish, a certificate will be issued to you recognising your participation as a stakeholder in CLEAR-PC.

- Yes
- No

14. If yes, please provide your email address and we will contact you to give you more information about the benefits of the network.

☐

Thank you very much for your collaboration! Your opinions will contribute to the development of a European strategy to improve health literacy and patient involvement in the prevention and treatment of prostate cancer.

Annex 5. Key health informant interview Gguide

CLEAR-PC – Task 5.1

Key Informant Interview Guide

1. Context:

This interview is part of the CLEAR-PC project, which aims to improve health and digital health literacy in prostate cancer across Europe.

- Your insights will help us understand existing tools, strategies, and gaps in this field.
- The interview will last around 20-25 minutes.
- With your permission, we will record the interview to get the transcript for analysis and reporting purposes.

0. Warm-up question

Q1. Could you briefly describe your role and experience related to health literacy, digital health literacy, or prostate cancer care?

- Do you work with patients, families, organizations, communities, health professionals?
- Which groups do you mostly engage with (age, education, socio-economic profile, etc.)?

1. Main interview questions

- **Tools & Strategies**

Q2. From your experience, what tools, initiatives, or strategies currently exist (at local, regional, or international level) to support health literacy or digital health literacy in cancer, especially prostate cancer, when applicable, for the general population, patients, healthcare professionals, and policymakers?

- Which platforms or materials are commonly used? Please provide material or links.
- In what formats are these strategies available (e.g., websites, apps, brochures, videos, guidelines, etc.)?

-**Successful initiatives & Transferability**

Q3. Based on your professional experience, are there any good practices or successful models (locally, nationally or globally) that could inspire or be adapted for prostate cancer prevention, diagnosis, treatment, or palliative care?

- What makes them successful?
- What would need adaptation for other contexts or countries?
- Have you seen a measurable impact?

- **Gaps & Challenges**

Q4. What do you see as the main gaps, barriers, or unmet needs in the field of health literacy for cancer patients, particularly vulnerable groups and men over 40?

- What challenges exist for people with low digital skills?
- Are messages adapted to different education levels, cultural contexts or gender needs?
- Do patients trust available information?

- **Stakeholders**

Q5. Which types of stakeholders (professionals, organizations, patient groups, and the general population) should play a key role in improving health literacy among prostate cancer patients and their families? Please indicate any specific profiles or groups you consider essential for strengthening future initiatives and collaborations.

- Role of patient associations or peer-support networks — please specify the profile.
- Relevant partnerships that could increase impact — please specify the profile.
- Contribution of technology companies and media — please specify the profile.

- **Future Directions**

Q6. Based on your experience, what actions, improvements, or research priorities do you consider essential for strengthening digital health literacy in the coming years?

- Which of the strategies you know would you adopt, maintain, or change?
- Which technological innovations would be most valuable?

- Which policies or investments are needed?
- Where is more evidence or impact evaluation required?

0. Closing

Q: Is there anything else you would like to add?

Q: Is there anything else you would like to add that you consider relevant for this topic?

Q: Thank you very much for your valuable time and contribution.

NOTES for the interviewee:

-Keep the interview flexible, open, and exploratory.

-Stakeholders may provide examples outside prostate cancer - this is encouraged – both in their countries, EU and outside EU

INFORMED CONSENT FOR ONLINE INTERVIEWS

- May we have your permission to record the interview session?
- By participating in this recorded interview, you are providing informed consent and acknowledging that the recordings will be transcribed verbatim subsequently.
- During the transcription process, the text will be handled with utmost confidentiality and will be anonymised to ensure that identification of individuals is not possible. The insights gained from the interview will be shared anonymously with the CLEAR-PC partners. The final analysis will be included in the reports for the European Commission and will be disseminated through CLEAR-PC channels.
- Kindly remember to keep your camera on throughout the duration of the interview.
- The interview is scheduled to last for 20-25 minutes, followed by a 5-minute summary and discussion.

Do you consent to these terms?

Annex 6. Verbatim quotes – Organisations, Networks and Participation

Categories	Code (KI)	Verbatim Organisations, Networks and Participation
Tools and Strategies	KI-026	"Estrategias autonómicas que involucran al tercer sector: Gobierno de Canarias: Canarias saludable Estrategias nacionales: Red de Escuelas de Salud para la Ciudadanía España. Asociaciones de pacientes: Asociación Española Contra el Cáncer (AECC)"
	KI-007	"Association for the Promotion of Self-Management (VFSM)"
	KI-033	"ANCAP Asociación Nacional de Cáncer de Próstata"
	KI-050	"Campañas de la Asociación Contra el Cancer. Hay diferentes campañas a lo largo del año que se repiten año tras año para ir calando mensajes. Ejemplo la Asociación en 2025 lanzó la campaña "Nos lo tomamos a pecho", creada por pacientes y supervivientes sobre cancer de mama"
	KI-015	"SMRC: Self Management Resource Center"
	KI-004	"En Cantabria se desarrollan varias iniciativas para mejorar la alfabetización en salud de la población. Destaca la Escuela Cántabra de Salud, que ofrece información fiable y comprensible, talleres y programas educativos para fomentar el autocuidado y la participación activa en la salud. El programa Paciente Activo promueve el aprendizaje entre iguales para mejorar el manejo de problemas de salud crónicos y la toma de decisiones informadas. En el ámbito del cáncer, los programas de cribado poblacional (como mama y colon) y la labor de la Asociación Española Contra el Cáncer en Cantabria contribuyen a mejorar el conocimiento, la prevención y el acompañamiento de las personas con cáncer y sus familias. En el caso del cáncer de próstata, no existe un programa específico, pero se trabaja la alfabetización en salud mediante información clara sobre prevención y decisiones informadas."
	KI-014	"Si bien a nivel nacional están las escuelas de salud de las diferentes comunidades autónomas, creo que la actividad de las mismas llega de forma desigual a profesionales y ciudadanos. Los programas en general pueden aportar incluso desde las propias experiencias de los pacientes, pero creo que quizás habría que mirar otros ámbitos para programas más innovadores como puede ser https://es-es.fastheroes.com/ que aunque viene de otro ámbito puede inspirar el desarrollo de programas más transversales"
	KI-031	"Marco estratégico Salud 2030 / Salud 2035" "El Ministerio de Salud de la República Checa cuenta con un plan estratégico a largo plazo para el desarrollo de la atención sanitaria, cuyo componente clave es el fortalecimiento de la alfabetización en salud de la población como un aspecto fundamental de la prevención primaria y la promoción de la salud. Estos documentos establecen objetivos sistemáticos, mecanismos de seguimiento y actividades planificadas para mejorar la alfabetización en salud de la población" "Asimismo, existe el Paciente Hub, una iniciativa destinada a mejorar la posición y el papel de las organizaciones de pacientes en la sociedad"
	KI-033	"Cáncer de próstata resistente a la castración UROLOGY CARE FUNDATION. ProstActivos. CONOCE TU PRÓSTATA. ASTELLAS. PROTAGONISTA. CONOCIENDO MÁS SOBRE EL IMPACTO DEL CÁNCER DE PRÓSTATA EN EL PACIENTE. NOVARTIS. Y muchos mas"

Categories	Code (KI)	Verbatim Organisations, Networks and Participation
	KI-033	"Reforzar el papel de las asociaciones de pacientes. En cáncer de próstata ANCAP es la única asociación concentrada exclusivamente en dar visibilidad y concienciación del diagnóstico precoz del cáncer de próstata. Dotar a las asociaciones ALTRUISTAS no PROFESIONALES CON EJECUTIVOS PACIENTES COBRANDO COMO SI TRABAJARAN EN UNA MULTINACIONAL"
	KI-045	"Conozco algunas. Algunas de ellas de aplican al ámbito del cáncer. No conozco ninguna específica en cáncer de próstata: Escuela Asturiana de Cuidados y otras escuelas de pacientes de Comunidades Autónomas y Asociaciones PACAS Asturias Care4Diabetes European Health Literacy Survey (HLS-EU) Específicas en cáncer: escuelas de pacientes de AECC y GEPAC"
	KI-050	"Conozco las Campañas de la Asociacion Contra el Cancer. Hay diferentes campañas a lo largo del año que se repiten año tras año para ir calando mensajes. Ejemplo la Asociación en 2025 lanzó la campaña "Nos lo tomamos a pecho", creada por pacientes y supervivientes sobre cancer de mama"
	KI-081	"Za prevencijui raka prostate napravio sam nove edukativne brošure za svoju Županiju, te osvjetlio Virovitički dvorac svjetlosnim efektima u plavo radi simboliziranja plave vrpce, održao emisiju Plave TV o raku prostete, sudjelovao na icv radiju, Pitomi radio i radio Slatina i HRT-u u vezi dizanje zdravstvene pismenosti o karcinomima; https://www.icv.hr/icv-radio/pricamo-o-zdravlju-benes-karcinomi-su-preventivni-i-ljudi-ih-ne-moraju-imati-samo-je-bitno-da-se-vise-vremena-posveti-vlastitom-zdravlju/ , https://magazin.hrt.hr/sretni-i-zdravi/strucnjaci-apeliraju-briga-za-zdravlje-krece-od-svakog-pojedinca-10893520 , https://www.radioslatina.hr/prevencijom-do-zdravlja/ , suradnja s udrugom nismo same u više navrata: https://nismosame.com/izvjestaj-o-radu/izvjestaj-o-radu-nismo-same-u-2023-godini-prvi-dio/ , Predavanja ispred Županijeke lige protiv raka kao član i predsjednik Lige itd..."
	KI-085	"Neću rak" je kampanja i nacionalni program u Hrvatskoj usmjeren na prevenciju raka vrata maternice, koji je gotovo u potpunosti preventabilan. Ključne mjere uključuju cijepljenje protiv HPV-a (glavnog uzročnika) i redovite ginekološke preglede (Papa test) za rano otkrivanje predstadija https://necurak.hzjz.hr/"
	KI-099	"Zdravko, smjernice za razvoj digitalne pismenosti Makarov DV, Feuer Z, Ciprut S, Lopez NM, Fagerlin A, Shedlin M, Gold HT, Li H, Lynch G, Warren R, Ubel P, Ravenell JE. Randomized trial of community health worker-led decision coaching to promote shared decision-making for prostate cancer screening among Black male patients and their providers. Trials. 2021 Feb 10;22(1):128. doi: 10.1186/s13063-021-05064-4. PMID: 33568208; PMCID: PMC7876807"
	KI-102	"Udruga Liga protiv raka Zadar postoji još od 1967. godine. Ciljevi i djelatnost Udruge su poticanje i organiziranje humanitarnih akcija za prikupljanje financijskih sredstava u svrhu kupnje neophodne medicinske opreme za onkološke bolesnike te pružanje psihosocijalne pomoći onkološkim bolesnicima i članovima njihovih obitelji."
	KI-107	"No tengo identificada ninguna iniciativa concreta. Sé por colaboraciónes internacionales y presentaciónes en congresos que en Australia hay un grupo que ha desarrollado varias guías o procesos de bunas prácticas, a través de the Australian Commission on Safety and Quality in Health Care."
Good practices and Initiatives	KI-102	"U studenom 2025. godine u suradnji s Ligom protiv raka Split te zadarskim brijačima organizirali smo bradatu aukciju te smo na taj način prikupili financijska sredstva za kupnju aparata za pomoć pri operacijama Urološkog odjela Opće bolnice Zadar."
	KI-090	"Libro inclusivo sobre cáncer de próstata usado en español e ingles. Muy demandado pel diferentes entidades"
	KI-003	"App móvil para que las personas frágiles realicen ejercicios: VIVIFRAIL"
	KI-007	"OHL-Self AsseT: used in primary care. Developed in Switzerland

Categories	Code (KI)	Verbatim Organisations, Networks and Participation
		Symptom Navi: Symptom Navi supports cancer patients in Switzerland in dealing with their cancer and the possible consequences of therapies and the disease."
	KI-035	"S obzirom na to da naša udruga okuplja studente, znanstvenike i liječnike koji se bave istraživanjem raka, dakle ne primarno liječenjem, sve inicijative koje su usmjerene na financiranje bazičnih istraživanja raka prostate, poput https://www.irb.hr/Novosti/Pet-zena-u-borbi-za-musko-zdravlje ili https://www.irb.hr/Novosti/Donacijom-13.193-eura-dm-devetu-godinu-zaredom-podrzao-istrazivanje-raka-prostate smatramo kao više nego dobrodošle u Republici Hrvatskoj"
Gaps and Challenges	KI-029	"Creo que la alfabetización en salud debe iniciarse en la etapa escolar, es necesario un verdadero cambio sociológico global de nuestra sociedad en relación a la responsabilidad personal con nuestra propia salud. Partiendo de esta premisa y, siendo realistas con la situación que nos ha tocado vivir, propongo utilizar la extensa red de atención primaria en Asturias para lanzar un programa de alfabetización en salud adaptado a los usuarios de cada territorio y sectorizado por necesidades de atención (sencillas o complejas), para el que se puede buscar la participación de los distintos Colegios de profesiones sanitarias que disponen de colectivos de profesionales jubilados, y no jubilados, dispuestos a colaborar con su Comunidad."
	KI-008	"En nuestra Comunidad Autónoma, creo que tenemos un reto grande debido al envejecimiento de la población, con lo que conlleva más comorbilidades, y los largos supervivientes, con los que se debería de tener protocolos de seguimiento y acceso al sistema sociosanitario claramente definidos. Pongo sociosanitario porque también está el tema de la soledad no deseada, y es preciso contar con una red importante para acompañar a este tipo de pacientes."
	KI-005	"Débil conexión entre escuelas, comunidades y sistemas sanitarios."
	KI-094	"Transmitir a la población de manera más concreta y directa información sobre los tipos de cáncer más frecuentes"
Recommendations	KI-002	"Integrar la alfabetización en salud en todo el itinerario asistencial (prevención/cribado, diagnóstico, decisiones de tratamiento, supervivencia y paliativos), no solo en campañas."
	KI-006	"Institucionalizar la alfabetización en salud como política pública. Medir lo que importa: comprensión y calidad de la decisión. Formar a profesionales y organizaciones, no solo informar a pacientes. Invertir en investigación de implementación. Reducir desigualdades, no aumentarlas. Dar poder real a pacientes y ciudadanía."
	KI-008	"En nuestra Comunidad Autónoma, creo que tenemos un reto grande debido al envejecimiento de la población, con lo que conlleva más comorbilidades, y los largos supervivientes, con los que se debería de tener protocolos de seguimiento y acceso al sistema sociosanitario claramente definidos. Pongo sociosanitario porque también está el tema de la soledad no deseada, y es preciso contar con una red importante para acompañar a este tipo de pacientes."
	KI-20	"Según mi experiencia, incidiría en desarrollar programas que promuevan organizaciones sanitarias alfabetizadoras, por ejemplo, simplificando el recorrido del paciente por el sistema y rediseñando los programas de cribado. La de toma de decisiones compartida entre profesionales y pacientes es una prioridad que creo que actualmente no se esta abordando."
	KI-031	"Principalmente capacitación para el público en general, para cuidadores informales, así como también formación formal sobre la comunicación con el paciente y su familia."
	KI-080	"Predavanja u zdrastvenim ustanovama"
	KI-103	"Na temelju iskustva u javnom zdravstvu, udrugama i u lokalnoj zajednici, potreban je sustavni, koordinirani i multisektorski pristup. Važna je integracija zdravstvene pismenosti u škole, zdravstvene ustanove i lokalne zajednice i potrebno je planirati izdvojena financijska sredstva za takve aktivnosti Potrebno je više uložiti u evaluaciju, učinke je potrebno mjeriti na lokalnom nivou, a ne samo na nacionalnom. Potrebno je jačati kompetencije zdravstvenih i odgojno-obrazovnih djelatnika, javnost također treba promijeniti paradigmu s kurative prema preventivi (premalo se vjeruje u moć prevencije)."

Categories	Code (KI)	Verbatim Organisations, Networks and Participation
	KI-109	"Plantearía un grupo de 5 cuestiones clave que deberían ser contestadas adecuadamente por la población tras una formación. Índice de pacientes que acuden al urólogo por ejemplo es otro parámetro"
	KI-088	"Es importante contar con la participación de la población de destino para conocer mejor sus necesidades y que puedan participar en el diseño de esas intervenciones."
Resources and links		https://www3.gobiernodecanarias.org/canariasaludable/ https://www.redescuelassalud.es/ https://selfmanagementresource.com/ https://vivifrail.com/es/documentacion/ https://m-pohl.net/ResultsEVPOP https://es-es.fastheroes.com/ http://www.gezondheidsvaaridhgeden.nl https://www.irb.hr/Novosti/Pet-zena-u-borbi-za-musko-zdravlje https://www.irb.hr/Novosti/Donacijom-13.193-eura-dm-devetu-godinu-zaredom-podrzao-istrazivanje-raka-prostate https://splsportugal.com/ https://hemed.hr/ https://hemed.hr/Default.aspx?sid=16783 https://www.icv.hr/icv-radio/pricamo-o-zdravlju-benes-karcinomi-su-preventivni-i-ljudi-ih-ne-moraju-imati-samo-je-bitno-da-se-vise-vremena-posveti-vlastitom-zdravlju/

Annex 7. Verbatim quotes – Digital Health Literacy

Categories	Code (KI)	Verbatim Digital health literacy
Tools and Strategies	KI-008	WHO: Global cancer observatory European Strategy: IDEAHL WHO: Código europeo contra el cáncer European Cancer Research: UNCAN EU
	KI-003	Me parece interesante en formato app para móvil donde te perimite realizar una table de ejercicio para personas frágiles https://vivifrail.com/es/documentacion/ El uso de redes sociales y aplicaciones de móvil
	KI-006	Hay vídeos https://www.escueladesaludmurcia.es/escuelasalud/mantenersalud/videos_urologia.jsf
	KI-004	Aunque en Cantabria no existen programas específicos de alfabetización en salud centrados únicamente en el cáncer de próstata, sí hay prácticas existentes que pueden adaptarse o servir de base, tales como: • Campañas sociales de concienciación sobre salud masculina y cáncer de próstata que aumentan la visibilidad y conocimiento básico. • Jornadas de humanización y diálogo entre profesionales y ciudadanía, que pueden transformarse en espacios educativos específicos. • Servicios de cuidados paliativos ya implementados que pueden incorporar materiales didácticos sencillos sobre qué son, cuándo aplicarlos y qué esperar. • Colaboración con AECC en espacios de atención al paciente, donde la información sobre opciones de tratamiento y apoyo práctico puede integrarse y reforzarse.
	KI-007	OHL-Self AsseT: used in prmary care (https://pubmed.ncbi.nlm.nih.gov/33352951/) Digital and navigational health literacy assessment in cancer survivors: using Swiss HLS19 Instruments (https://academic.oup.com/eurpub/article/35/Supplement_4/ckaf161.267/8303201?login=false) Symptom Navi: Symptom Navi supports cancer patients in Switzerland in dealing with their cancer and the possible consequences of therapies and the disease. The Association for the Promotion of Self-Management (VFSM) is a non-profit organization. With Symptom Navi, it promotes partnership-based cooperation between cancer patients and specialists across the entire care chain. (https://symptomnavi.ch/de/)
	KI-008	Global cancer observatory https://gco.iarc.fr/en, IDEAHL https://ideahl.eu/, Código europeo contra el cáncer https://cancer-code-europe.iarc.who.int/, UNCAN EUhttps://uncan.eu/a-role-for-patients-and-citizens/,
	KI-011	A nivel nacional: • Red española de alfabetización para la salud (https://www.alfabetizacionsalud.com/): red de profesionales con el interés común de contribuir a mejorar el sistema de salud a partir de uno de sus pilares básicos, la alfabetización para la salud. Trabajan a través de proyectos en colaboración, de forma abierta a otras iniciativas y organizaciones con intereses en el ámbito de la alfabetización para la salud y su aplicación en las soluciones de salud digital. • PyDeSalud (https://pydesalud.com/): plataforma web (abierta y gratuita) de servicios integrados cuyo objetivo es promover el conocimiento, la autonomía y la participación activa de la ciudadanía en el cuidado de su salud.

Categories	Code (KI)	Verbatim Digital health literacy
		• Estrategia de Salud Digital del SNS (https://www.sanidad.gob.es/areas/saludDigital/doc/Estrategia_de_Salud_Digital_del_SNS.pdf): aspira a contribuir al mantenimiento de un buen nivel de salud en la población española y a fortalecer el sistema sanitario público mediante la capacidad transformadora de las tecnologías digitales dirigida a personas, profesionales de la salud, organizaciones proveedoras de servicios sanitarios y resto de agentes relacionados. • Guía Salud.es (https://portal.guiasalud.es/material-pacientes): ofrece materiales para pacientes, familiares y cuidadores para ayudarles a comprender las recomendaciones de las Guías de Práctica Clínica (GPC) y Otros Productos Basados en la Evidencia (OPBE). También ofrecen información necesaria para facilitar la toma de decisiones y para mejorar la comunicación médico-paciente. • Canal POC (Point Of Care) (https://educacionpapps.blogspot.com/2024/04/que-es-una-canal-poc-point-of-care-en.html): medio o método que se utiliza para proporcionar información y educación relevante a los pacientes justo en el punto de atención médica. Este tipo de canal es especialmente valioso en entornos clínicos de Atención Primaria y hospitales, donde la información puede ser entregada de manera efectiva y oportuna a los pacientes durante su atención médica. • Proyecto IDEAHL (Improving Digital Empowerment for Active Healthy Living) (https://www.astursalud.es/noticias/-/noticias/proyecto-ideahl): promover estilos de vida más saludables en el marco de la Unión Europea (UE), así como mejorar la gestión de la salud y la interacción con los profesionales sanitarios a través de herramientas e iniciativas digitales. • Osasun Eskola (https://osasuneskola.osakidetza.eus/es/home): ofrece información y formación de una forma más interactiva para favorecer un aprendizaje intuitivo y dinámico. • Escuela Andaluza de Pacientes (https://www.easp.es/project/escuela-de-pacientes-2/): formación de pacientes crónicos y sus familiares para mejorar su autocuidado y la autogestión de sus enfermedades. Ámbito oncológico: • Guías de Comunicación en Oncología: Aspectos Transversales y Durante el Cuidado (GuíaSalud y SESCS) (https://portal.guiasalud.es/wp-content/uploads/2025/09/ot_5_2_guias-de-comunicacion-en-oncologia_aspectos-transversales-y-durante-el-cuidado_def_sescs.pdf) • Organizaciones como la AECC (Asociación Española Contra el Cáncer) y el GEPAC (Grupo Español de Pacientes con Cáncer) ofrecen recursos, apoyo y sensibilización. • Estrategia en Cáncer del Sistema Nacional de Salud 2021 (https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/cancer/docs/ESTRATEGIA_EN_CANCER_DEL_SNS.pdf) Cáncer de próstata: • Herramienta de Ayuda para la Toma de Decisiones compartida en Cáncer de Próstata (https://www.madrid.org/bvirtual/BVCM017405.pdf): 2011. • Reino Unido (https://prostatecanceruk.org/risk-checker): check your risk in 30 seconds. • AECC (https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata): Guía Práctica para el cáncer de próstata (2004): https://www.contraelcancer.es/sites/default/files/migration/actualidad/publicaciones/documentos/guiaprostata.pdf
	KI-012	European proyect: INTERVENE diagnosis, and personalised treatment by utilizing a large, integrated pool of genomic and health data from Europe and the USA. https://cancerpatientseurope.org/intervene/
	KI-013	Conozco escalas de medicion de la alfabetizacion en salud como HLS questionnaire (validado al español) o HLQ también validado al español. Particularmente para cáncer, no conozco estrategias puntuales aunque si esta revisión https://www.sciencedirect.com/science/article/pii/S1462388924000802. También el proyecto CURTAIN Boosting Cancer Literacy Across Europe (2025-2028) https://curtainproject.eu/ Estrategias conozco la del proyecto IDEAHL.

Categories	Code (KI)	Verbatim Digital health literacy
	KI-015	Our organization has six program to promote health literacy. One of them is Cancer Thriving and Surviving aimed at cancer survivors after initial treatment. We have also worked with a group in the Netherlands to create an end of life self-management program for people with cancer. Both of these include prostate cancer but are not specific.
	KI-022	Teach-Back (Internacional/Colombia): Técnica de "comprobar la comprensión" donde el paciente explica con sus palabras lo entendido. Es clave en la consulta oncológica del INC. Colombia - Guía de Práctica Clínica para la detección temprana, diagnóstico, tratamiento integral, seguimiento y rehabilitación de cáncer de próstata - Guía para pacientes y cuidadores (2025) INC - UNAL: https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/INEC/IETS/Cancer-prostata-final-pacientes%20final.pdf La guía fue diseñada con estrategias de lenguaje simple, confirmación de aprendizaje, traducción de lenguaje técnico a lenguaje sencillo y guía de conversación con equipo tratante. Colombia - Ponte la titular / Hablemos de Próstata (Liga Colombiana Contra el Cáncer): Estrategia que en alianza con la División Mayor del Fútbol Colombiano (Dimayor), futbolistas y directivos de los clubes de futbol posicionaron mensajes en sus redes sociales y medios de difusion con el hashtag #hablemosdeprostata, desarrollo de la página Ponte la titular, con lenguaje futbolístico e imágenes de futbolistas reconocidos del país acompañando información sobre prevención, diagnóstico y tratamiento de CA de próstata https://www.ligacancercolombia.org/cancer-de-prostata-3/ Colombia - MitoHomes - ProstataHome: Estrategia de desmitificación alojada en la página de la Liga Colombiana contra el Cáncer. Microcápsulas informativas que deconstruyen los principales mitos de diversos tipos de cancer, entre ellos el de próstata https://www.ligacancercolombia.org/dia-mundial-del-cancer/#prostata. Colombia - AstraZeneca y AXXA seguros - Club Pro - página con recursos para pacientes de cáncer de próstata sobre educación, nutrición, estilo de vida saludable con enfoque de familia Comunidad de pacientes. https://pacientesconectandojuntos.co/club-pro/#:~:text=Club%20pro%20%2D%20%C2%A1Bienvenidos%20a%20Conectando%20Juntos! Movember (Internacional): Estrategia global que financia investigación y crea campañas de de comunicación visual para sensibilizar sobre salud masculina y cáncer de próstata. Enlace Movember. https://ex.movember.com/report-cards/index/report_category/prostate-cancer
	KI-29	Desconozco iniciativas concretas que se dirijan a la alfabetización en salud. Lo más cercano que puedo aportarles es el programa europeo de adquisición de competencias digitales que incluye a las profesiones sanitarias y se está desarrollando actualmente en España liderado por Unión profesional y ejecutado por los Colegios Profesionales. https://upro.es/.
	KI-030	Além do site desta Associação - www.apdprostata.com, só temos conhecimento de literacia no site da APU - Associação Portuguesa de Urologia.
	KI-032	Health literacy is a recognised priority at both European and Portuguese levels, with several tools, programmes and strategies currently in place to improve citizens' ability to access, understand and use health information. At the European level, health literacy is inserted in public health policies such as EU4Health and

Categories	Code (KI)	Verbatim Digital health literacy
		Europe's Beating Cancer Plan, which emphasise prevention, early detection, informed decision-making and the reduction of health inequalities. Within this framework, specific projects address cancer-related health literacy.
	KI-036	Educational campaigns by medical professionals and primary care physicians about PSA screening in adults.
	KI-037	Da , naše društvo Europa Uomo Slovenija , Društvo uroloških bolnikov sprovodi mentorsko savetovanje bolestnicima sa rakom prostate (bolestnik bolestniku), djelimo liflete na predavanjima, ambulantama na perimarnom i sekundarnom nivou i održavamo +- barem 20 predavanja za osaveštavanje, nasupamo u medijima... bili smo iniciator uvodjenja presejavanja raka prostate u Slovniji u 2022 i 2024 koji je počeo kao projepat PETER krajem novembra 2025....
	KI-043	Existem algumas ferramentas e projetos que representam boas práticas na promoção da literacia em saúde (senso lato) na área do cancro - inclui pelo menos dois projetos na área do cancro da próstata. Deixo aqui 2 bases de dados que podem interessar ao vosso projeto: https://pieces.itfits-toolkit.com/repositorysearch
	KI-044	In Egypt, health literacy initiatives exist but are limited, fragmented, and not systematically applied to cancer care, particularly prostate cancer. General health literacy programs, mainly led by the Ministry of Health and NGOs focus on non-communicable diseases such as diabetes and hypertension. Cancer-related health literacy is largely concentrated on breast cancer, with minimal attention to male cancers. Cancer education is usually delivered after diagnosis within oncology centers through verbal counseling, which is clinician-dependent and not standardized. There are no national non digital programs addressing prostate cancer prevention or early diagnosis. Digitally, patients rely heavily on social media (Facebook, YouTube) and individual physician or hospital pages. However, no official digital platforms are providing evidence-based, Arabic-language tools for prostate cancer screening, treatment decision making, or palliative care. Decision aids and shared decision-making tools are not routinely used. Overall, no structured digital or non digital health literacy tools specific to prostate cancer are currently implemented in Egypt. This represents a major gap and an opportunity to develop culturally appropriate, Arabic language interventions covering prevention, early diagnosis, treatment choices, and palliative care.
	KI-046	pREDAVNJA OPĆOJ POPULACIJI, JAVNOZDRAVSTVNE BROŠURE SPECIFIČNO PRILAGOĐENE DOBNOJ SKUPINI OBOLJELIH, FACEBOOK ČLANCI, VIJESTI NA WEBU, OBILJEŽAVANJE DNA/ TJEDNA RAKA PROSTATE, SUDJELOVANJE O EMISIJAMA O RAKU PROSTATE, IZRADA STATISTIČKIH IZVJEĆA ŽUPANIJI O RAKU KOJA SADRŽI I INFO O RAKU PROSTATE.
	KI-048	YES for health literacy in general: there is a national HL alliance with 5 areas of work: (1) improving the quality of communication in healthcare; (2) improving the quality of written / audio-visual health information in relation to health promotion, prevention and treatment; (3) organizational health literacy (provision of tools for hospitals, primary care and some non-healthcare settings such as extra curricular youth work); (4) empowering patients and citizens to adquately take care of themselves including adquate usage of the healthcare system; (5) HL measurement. (1) and (2) are specifically implemented in cancer care. As part of the national health information strategy, Austria has an online health information portal that offers information about many different diseases including cancers in a quality-assured way (https://www.gesundheit.gv.at/index.html) which is continuously further developed.

Categories	Code (KI)	Verbatim Digital health literacy
		For more information (in German) see https://oepgk.at/# then click on "Schwerpunkte" where the 5 areas are described in detail. I am not aware of specific strategies / tools for prostate cancer.
	KI-065	Programa "Com a Saude nao se brinca": https://splsportugal.com/ Literacia em Oncologia: "Todos Contam!" – AEOP & SPLS (https://congresso.aeop.pt/2025/05/30/literacia-em-oncologia-todos-contam/)
	KI-069	Actividades desenvolvidas pelas diferentes sociedades médicas junto da população, particularmente próximo dos dias ou dos meses que anualmente são dedicados à patologia oncológica em questão. No caso do cancro da próstata e demais doenças específicas do homem.
	KI-069	Sim, por exemplo a excelente iniciativa "Tratar o Cancro por Tu" (https://tratarocancroportu.pt/). A estratégia Portuguesa de Luta contra o cancro, através do National Cancer Hub através do seu stakeholder's group promoveu a organização de um grupo de trabalho sobre Informação em Saúde (https://aicib.pt/wp-content/uploads/2022/02/National-Cancer-Hub-Portugal_Jan22.pdf).
	KI-072	Entendiendo el concepto de alfabetización como algo amplio podría plantearse lo siguiente: el programa de salud con Z de ámbito autonómico y local; Canarias Saludable o la Escuela de pacientes, aunque este último surge de un proyecto que se inició en otras CCAA. A nivel internacional se puede considerar el proyecto DIPEx (Health Experiences) y, en España DIPEx España, como herramientas que apoyan la educación en salud pero no es ese su objetivo principal sino ofrecer información basada en experiencias de pacientes y educar al personal sanitario. En cáncer hay otros países del proyecto DIPEx que tienen sus web abordando este tema (aunque sí existe un módulo sobre cuidados paliativos que incluye oncología y patologías no oncológicas tanto desde la perspectiva de pacientes como familiares), incluyendo el de cáncer de próstata, aunque en España no lo tenemos abordado aún. Por otro lado, trabajo en un proyecto de divulgación científica utilizando el arte, con el fin de provocar cambios sociales y disponible en abierto en la web MUSAExperience. La web de la OMS me parece muy relevante para abordar los bulos y la desinformación e informar y explicar sobre salud.
	KI-073	Estrategia de abordaje a la Cronicidad, Escuela de Pacientes de Canarias, Aulas de Salud Estrategia del dolor crónico no oncológico, Prevención y control de la Enfermedad Vascular ateroesclerótica (EVA), Proceso asistencias integrado del sobrepeso y la obesidad en Canarias, Diagnostico precoz del Cáncer de mama, entre otros .
	KI-079	O Guia de Recursos para a Pessoa com Doença Oncológica e seus Cuidadores (https://aicib.pt/2025/07/01/ja-esta-disponivel-a-2a-edicao-do-guia-de-recursos-para-a-pessoa-com-doenca-oncologica-e-seus-cuidadores/). A Sociedade Portuguesa de Literacia em Saúde também promove vários recursos para aumentar a literacia em saúde.
	KI-081	Zdravko ai digitalni asistent i gina ai rak vrata maternice od HZJZ-a, nacionalni program ranog otkrivanja raka, dojke, debelog criojeva, pluća i raka vrata maternice. Europski plan pobjeđivanja raka. https://www.vpz.hr/2021/11/virovitici-odrzana-javnozdravstvena-akcija-mjesec-borbe-raka-naglasak-stavljen-prevenciju-rano-otkrivanje/ , https://www.zzjzvpz.hr/index.php?sadrzaj=djelatnost&dj=3&djtxt=novostijavvise&novtxt=657
	KI-082	In the United Kingdom there isn't a single nationwide programme for health literacy, but rather a mix of national strategies, local initiatives, workforce training, practical tools, partnerships and community-focused approaches designed to help people access, understand, and use health information effectively. These operate at different levels (policy, health systems, local communities and individual support) and target both the general public and health professionals.
	KI-084	Screening voor darmkanker via brief of huisarts met ifobt test.
	KI-088	"Sí. Los enfermeros referentes de los centros educativos de la comarca del Campo de Gibraltar realizan talleres de promoción de la salud en los centros escolares. Aunque estos talleres no están diseñados específicamente para trabajar y mejorar dimensiones concretas de la alfabetización en salud, su puesta en marcha contribuye a mejorar algunos componentes de la alfabetización en salud.
	KI-092	"Eerder algemeen: Eerder algemeen:

Categories	Code (KI)	Verbatim Digital health literacy
		- Verschillende workshops in de wijk in samenwerking met centrum voor volwassenonderwijs rond digitale gezondheidsvaardigheden bij wijkbewoners - Apps voor mensen met lage gezondheidsvaardigheden: bijv. LeesSimpel App - Opleiding bij onze professionals rond gezondheidsvaardigheden - Verschillende tools en hulpmiddelen voor professionals: terugvraagmethode, visuele ondersteuning (beeldmateriaal, maar ook bestaande websites met eenvoudige info zoals Zanzu...) - Websites met info over gezondheidsvaardigheden: via Gezond Leven (https://www.gezondleven.be/themas/gezondheidsongelijkheid/drempels-voor-een-gezonde-leefstijl-bij-mensen-in-maatschappelijk-kwetsbare-situaties/wat-zijn-gezondheidsvaardigheden-en-waarvoor-dienen-ze), en stad Gent (https://www.eerstelijnszone.be/vormingsaanbod-gezondheidsvaardigheden-gent). Ook Pharos is een gekende organisatie.
	KI-094	Conozco las páginas web de la Sociedad Española de Medicina y de la Asociación Española contra el cáncer
	KI-095	Si. Algunas se aplican en el ambito del cancer
	KI-096	mICardiApp para pacientes con Insuficiencia Cardíaca. Mentoring para enfermos renales, entre otros. Para pacientes con cáncer, la Asociación Española Contra el Cáncer dispone de una serie de servicios y programas para la atención integral de las personas con cáncer de próstata. Desconozco otras iniciativas en concreto.
	KI-0103	U Europi zdravstvenu pismenost oblikuju EU institucije kao što su SZO, OECD, neke mreže kao što je EuroHealtNet, UNICEF i drugi. Hrvatska nema zasebnu strategiju zdravstvene pismenosti već je ona integrirana kroz različite strategije, npr. Strategiju razvoja zdravstva, različite programe promicanja zdravlja, nacionalne preventivne programe, programe ranog otkrivanja (kroničnih nezaraznih bolesti i programe ranog otkrivanja raka), kroz strategije obrazovnog sustava, kroz različite edukacije, projekte i kampanje. Ministarstvo zdravstva daje zakonodavni okvir. Na lokalnoj razini, kao što je Međimurska županija također ne postoji konkretna strategija, no u Planu razvoja Međimurske županije do 2027. godine postoji dio koji se odnosi na zdravstvo (https://medjimurska-zupanija.hr/strateski-dokumenti/) i koji uključuje i zdravstvenu pismenost, postoji i jedan dokument koji više nije aktualan Strateški plan za unapređenje zdravlja i smanjivanje nejednakosti u zdravlju u Međimurskoj županiji od 2014.-2020. godine (chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://zzjz-ck.hr/upload/publikacije/Strate%C5%A1ki%20plan%20za%20unapre%C4%91enje%20zdravlja%20i%20smanjivanje%20nejednakosti%20u%20zdravlju%20u%20Me%C4%91imurskoj%20%C5%BEupaniji%20od%202014.-2020.pdf), ali je bio prvi dokument u RH za smanjivanje nejednakosti u zdravlju - chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://zzjz-ck.hr/wp-content/uploads/2014/04/Strategic-plan-for-tackling-health-inequalities-in-Medimurje-County-through-health-promotion-ENG-FINALFINAL.pdf .
	KI-104	"In het algemeen rond gezondheidsvaardigheden: ja. Vanuit de wijkgezondheidscentra volgen we dit onderwerp op. We proberen op de hoogte te blijven van nieuwe hulpmiddelen of methodieken (bv. rond vaccinatie, algemene gezondheidsinformatie, digitale gezondheidsvaardigheden,...).
Good practices and Initiatives	KI-004	Aunque en Cantabria no existen programas específicos de alfabetización en salud centrados únicamente en el cáncer de próstata, sí hay prácticas existentes que pueden adaptarse o servir de base, tales como: • Campañas sociales de concienciación sobre salud masculina y cáncer de próstata que aumentan la visibilidad y conocimiento básico. • Jornadas de humanización y diálogo entre profesionales y ciudadanía, que pueden transformarse en espacios educativos específicos. • Servicios de cuidados paliativos ya implementados que pueden incorporar materiales didácticos sencillos sobre qué son, cuándo aplicarlos y qué esperar. • Colaboración con AECC en espacios de atención al paciente, donde la información sobre opciones de tratamiento y apoyo práctico puede integrarse y reforzarse.
	KI-008	UNCAN EUhttps://uncan.eu/a-role-for-patients-and-citizens/, Plan europeo contra el cáncer (diversas iniciativas emblemáticas), https://commission.europa.eu/topics/public-health/european-health-union/cancer-plan-europe_es

Categories	Code (KI)	Verbatim Digital health literacy
	KI-011	• Risk checker UK: https://prostatecanceruk.org/risk-checker: evaluador de riesgo. • PSA Test (https://www.nhs.uk/tests-and-treatments/psa-test/): análisis de sangre que ayuda a detectar afecciones de la próstata, como cáncer de próstata o agrandamiento de la próstata. • User-testing an interactive option grid decision aid for prostate cancer screening: lessons to improve usability: https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/ • Knowing Your Options (https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options): permite a los pacientes recién diagnosticados, que se enfrentan a varias opciones de tratamiento diferentes, ingresar sus propios parámetros personales de cáncer, como PSA y otros resultados de pruebas, en un enlace web seguro que analiza sus datos y establece su gama completa de opciones, con riesgos y beneficios específicos para esa persona. • Código Europeo de Prácticas en el Oncología (https://www.europeancancer.org/content/european-code-of-cancer-practice.html) • Mac Millan Cancer Support (https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions): ayuda a comprender opciones de tratamiento.
	KI-012	iNTERVENE study - digital intervention to improve cancer literacy https://cancerpatientseurope.org/intervene/
	KI-013	OPHELIA- de Richard Osborne de Australia https://healthliteracydevelopment.com/who-can-use-ophelia/
	KI-021	https://ideahl.eu/ https://saludextremadura.ses.es/web/ https://www.educarex.es/programas-educativos/educacion-para-la-salud.html
	KI-022	Colombia - La experiencia de Colombia con el programa Ponte la titular / Hablemos de Próstata (Liga Colombiana Contra el Cáncer) parece muy interesante, ya que el entorno del fútbol moviliza y concentra entre sus seguidores gran parte de la población masculina. Vale la pena explorar su experiencia y replicarla. México - Instituto para el Desarrollo de Masculinidades Anti Hegemónicas IDMH https://demachosahombres.com/ / Plataforma #DeMachosaHombres https://www.instagram.com/demachosahombres/ Equipo de México que ha creado una sólida plataforma para tratar temas relacionados con la salud y el bienestar masculinos. Buena penetración en medios digitales y articulación de comunicaciones estratégicas para campañas de promoción y prevención en diversos temas.
	KI-036	I think online and social media campaigns on Facebook, Instagram, and TikTok can be highly impactful on medical education and improve participation in screening programs.
	KI-037	Predavanja, školovanje mentora, promocijski i ošaveštvajući materjali, prisustvo na događajima, novinarskim konferencijama u medijima in na našoj web stranici www dub. si Na Europskom nivou kademija i obuka sa strane EUROPA UOMO
	KI-040	Not a successful one clinically Movember is helpful Austrian loose tie program
	KI-043	Para além das referências colocadas em cima, posso mencionar dois projetos nossos que podem ser interessantes analisar neste contexto: www.2minutos.pt www.tratarocancroportu.pt

Categories	Code (KI)	Verbatim Digital health literacy
	KI-044	1-National Cancer Institute, Egypt (Cairo University) Provides patient education, counseling, and outreach programs that can be adapted for prostate cancer through standardized leaflets, digital decision aids, and awareness campaigns. 2-Ministry of Health and Population (MoHP) Egypt Runs public health campaigns on non-communicable diseases and cancer awareness (mostly breast cancer) that can be adapted by large-scale media campaigns targeting men for early detection, PSA screening 3-European level: Unfortunately, I don't know
	KI-045	Care4Diabetes
	KI-048	Austrian best practice example: quality of communication in oncology is a training for oncologists and other healthcare staf in oncology in patient centres communication, with the aim to improve patients' understanding of their diagnosis and treatment.
	KI-049	For Latvia, the initiatives have not been very successful
	KI-051	Duidelijke uiteg over prostaatkanker en het testen hiervan via thuisarts.nl voor de patient, met ook voor- en nadelen, risico-inschatting
	KI-053	In Slovenia we have very good experiences with the three existing cancer screening programmes (breast, cervical and colon cancer screening programmes) that are very good starting point for all of the activities for prostate cancer.
	KI-055	A série "2' Minutos para mudar de vida" é uma produção portuguesa de ficção para educação para a saúde, focada na prevenção de doenças não transmissíveis, como o cancro, promovendo mudanças de comportamento através de histórias curtas e práticas, exibida na RTP e disponível online.
	KI-058	Sensibilização através dos midia (rádio, TV, jornais) Rastreios nos centros de saúde (PSA)
	KI-062	Mais informação sobre a classe mais desfavorecida , dar conhecer porta a porta "o que é muito "dificil "os centros saúde tem esse papel importante com seu medico e enfermeiros .Embora ja exista a preocupação de ser divulgado.
	KI-066	O Serviço de Urologia do CHUC desenvolve anualmente um jantar solidário, do qual faz colecta de fundos para uma instituição de solidariedade. A actividade tem por objectivo criar um foco de interesse para dar a conhecer a problemática das doenças do homem.
	KI-069	Para além da iniciativa "movember" desconheço iniciativas especificamente viradas para literacia em torno do cancro da próstata
	KI-072	Considero que Canarias Saludable es una herramienta de utilidad para informar a la ciudadanía. En relación a los cuidados paliativos podría recomendar el módulo de cuidados paliativos de DIPEx España.
	KI-074	Our association offers discussion groups that have been quite successful.
	KI-079	O Guia de Recursos para a Pessoa com Doença Oncológica e seus Cuidadores (https://aicib.pt/2025/07/01/ja-esta-disponivel-a-2a-edicao-do-guia-de-recursos-para-a-pessoa-com-doenca-oncologica-e-seus-cuidadores/).
	KI-082	Prostate Cancer UK Education provides free online courses and webinars aimed at clinicians and care teams to support informed conversations in primary and secondary care. Topics include awareness, early detection, treatment side-effects, and supportive care, with some content touching on palliative care and shared decision-making. Organisations like Prostate Cancer UK and Cancer Research UK produce fact sheets, helplines, FAQs and booklets that break down prostate

Categories	Code (KI)	Verbatim Digital health literacy
		disease, diagnosis and treatment into clear language for patients and carers. Although there isn't a universal NHS prostate cancer screening programme, risk communication tools (e.g., risk checkers and decision discussions supported by clinicians) help individuals consider whether PSA testing and further assessment make sense for them based on personal risk factors.
	KI-072	Considero que Canarias Saludable es una herramienta de utilidad para informar a la ciudadanía. En relación a los cuidados paliativos podría recomendar el módulo de cuidados paliativos de DIPEx España.
	KI-084	Standaard PSA screening via de huisarts in het bloed vanaf een bepaalde leeftijd.
	KI-085	Razina RH- gina AI- digitalna asistentica HZJZ, alat razvijen u sklopu prevencije raka maternice, generalno u smislu modela povećanja zdravstvene pismenosti
	KI-087	Desde la Universidad de Cádiz, en colaboración con otros profesionales de diversas instituciones, estamos llevando a cabo un proyecto de mHealth para fomentar la alfabetización en salud y la autogestión de los pacientes con insuficiencia cardíaca. Se ha codiseñado una app de salud dirigida a estos pacientes. Actualmente estamos en la fase de validación de la herramienta en el ámbito clínico.
	KI-088	MiCardiApp considero que ha sido una buena práctica, ya que en su desarrollo se tuvieron en cuenta las necesidades reales de los pacientes. A partir de la identificación de esas necesidades, se definieron y elaboraron los contenidos que debían incluirse en la aplicación.
	KI-092	- Via een vertrouwensband met de huisarts: wij sturen bijv. jaarlijks een zeer eenvoudige en persoonlijke uitnodiging voor een griepvaccinatie vanuit onze wijkgezondheidscentrum - Visueel beeldmateriaal - Eenvoudige info in de wachtzaal van ons wijkgezondheidscentrum - Info delen via groepen die al samenkomen, via de vertrouwenspersoon die het aanspreekpunt is van deze groepen
	KI-093	Podcast, short en redes...
	KI-095	La fundacion FEFOC trabaja mucho en iniciativas en el cancer y especificsmente en el de prostata
	KI-099	https://health.ec.europa.eu/non-communicable-diseases/cancer/europes-beating-cancer-plan-eu4health-financed-projects/projects/clear-pc_en?utm_source=chatgpt.com
	KI-103	Uspješni programi su npr. Nacionalni program Živjeti zdravo (proizašao iz EU projekta Živjeti zdravo) kojega koordinira Hrvatski zavod za javno zdravstvo, a koji se provodi u svim županijama, Nacionalni programi ranog otkrivanja raka (dojke, debelog crijeva, pluća, pilot projekt ranog otkrivanja vrata maternice i pilot projekt ranog otkrivanja raka prostate), koje također koordinira HZJZ, a provode se u svim županijama (pilot za vrat maternice je u Virovitičko-Podravskvoj županiji, a za prostatu u Zagrebu). U sklopu Projekta Živjeti zdravo provodilo se istraživanja o Zdravstvenoj pismenosti u području mentalnog zdravlja djece i mladih (https://www.hzjz.hr/sluzba-promicanje-zdravlja/zdravstvena-pismenost-odgojno-obrazovnih-djelatnika-u-podrucju-mentalnoga-zdravlja-djece-i-mladih/) i drugi programi. U Međimurskoj županiji Zavod za javno zdravstvo Međimurske županije u suradnji s brojnim dionicima provodi brojne programe promicanja zdravlja i programe zdr. pismenosti. Vrlo uspješno provodi Nacionalne programe ranog otkrivanja raka dojke i debelog crijeva, usko surađuje s Županijskom ligom protiv raka Čakovec i drugim ustanovama i udrugama, provodi brojne programe promicanja zdravstveno usmjerene tjelesne aktivnosti, u sklopu Savjetovališta za prevenciju i tretman prekomjerne tjelesne mase i debljine ima edukativno - suportivnu grupu jednom mjesečno od 2013. godine u kojoj se obrađuju brojne teme s ciljem unapređenja zdr. pismenosti, pa i vezano uz rak prostate. Županijska liga protiv raka Čakovec je vrlo važan dionik zdravstvene pismenosti u Međimurskoj županiji - osnovana je 1998. godine (djeluje već više od 28 godina), okuplja 5 klubova oboljelih, među njima i Klub oboljelih od raka prostate (osnovan 2010. godine), a u svojem djelovanju usko surađuje s Zavodom za javno zdravstvo Međimurske županije, Srednjom školom Čakovec, svim drugim zdravstvenim ustanovama te školama i medijima. Zdravstvena pismenost se

Categories	Code (KI)	Verbatim Digital health literacy
		provodi kroz edukaciju, javnozdravstvene akcije, podršku pacijentima, humanitarno-edukativne akcije, kulturne manifestacije i dr. U Međ. županiji se već dugi niz godina provodi javnozdravstvena kcija Kestenijada, posvećena raku prostate. Županijska liga protiv raka MŽ je izdala i monografiju u kojoj su detaljno opisane sve aktivnosti. Ima i svoju web i facebook stranicu, koje su također kanali zdr. pismenosti (iste kanale koristi i ZZJZ MŽ). Na Nacionalnom nivou je uvedena i nova platforma zdr. pismenosti - ZdrAVKO!
	KI-105	We merken samen met gezondheidsgidsen, wat op zich een heel succesvol initiatief is. Ze kunnen mensen begeleiden in het zorglandschap.
	KI-106	Ongoing awareness about prostate cancer through various initiatives and campaigns.
	KI-111	https://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/arxius/ICOPraxis_prostata_castellano-versiAn-completa.pdf
	KI-112	El Programa de detección precoz del cáncer de mama la Xunta de Galicia es una referencia en alfabetización masiva, tras 34 años de implantación: -Accesibilidad de la información: existe una gran difusión de información sobre este cribado en medios físicos y digitales -Envío de notificaciones personalizadas que explican no solo la cita, sino el por qué del rango de edad (50-69 años), el significado de los resultados, y las ventajas y efectos indeseables posibles. Galicia mantiene una de las tasas de participación más altas de España, lo que indica un éxito en la "alfabetización en prevención"
	KI-105	We merken samen met gezondheidsgidsen, wat op zich een heel succesvol initiatief is. Ze kunnen mensen begeleiden in het zorglandschap.
	106	Ongoing awareness about prostate cancer through various initiatives and campaigns.
	KI-005	Enfoques centrados en la enfermedad y no en la promoción de la salud.
	KI-091	Debería haber más informaicón para derribar tabús
	KI-100	Strong, unfortunately negative influence of social networks, individual ignorance of how to seek reliable information, distrust in the healthcare system.
	KI-105	Ik denk aangepaste berichtgeving (meer toegankelijk taalgebruik) Ook initiatieven om laagdrempelig uitleg van deze initiatieven te geven zodat mensen een geïnformeerde keuze kunnen maken.
	KI-109	La lucha contra la desinformación
	KI-111	Toma de decisiones compartidas insuficiente, desigualdades sociales, información digital de calidad variable, comprensión limitada de información médica compleja...
Recommendations	KI-003	El uso de redes sociales y aplicaciones de móvil
	KI-004	En primer lugar, incorporar la alfabetización en salud como una prioridad transversal en las políticas públicas, no solo en sanidad, sino también en educación, servicios sociales y ámbito comunitario. Esto incluye exigir lenguaje claro, información comprensible y apoyo a la toma de decisiones en todos los servicios de salud. En segundo lugar, es clave evaluar no solo el nivel de conocimiento de la población, sino su capacidad real para comprender, decidir y actuar. La investigación debería centrarse en medir la comprensión práctica, el impacto en la calidad de vida y la reducción de desigualdades, especialmente en poblaciones vulnerables. Otra prioridad es invertir en investigación aplicada, que analice qué formatos, mensajes y entornos funcionan mejor (presencial, digital, comunitario), y que implique a pacientes y ciudadanía en el diseño y evaluación de las intervenciones. También es necesario formar a los profesionales sanitarios en comunicación, alfabetización en salud y toma de decisiones compartida, evaluando cómo estas competencias influyen en resultados clínicos y experiencia de las personas.

Categories	Code (KI)	Verbatim Digital health literacy
		Por último, reforzar las estrategias comunitarias y de participación, apoyando redes locales, asociaciones de pacientes y programas de educación entre iguales, así como promover el uso responsable de herramientas digitales para combatir la desinformación.
	KI-09	training for health care professionals and greater implementation of Health coaching
	KI-013	Poner en práctica la estrategia del proyecto IDEAHL por ejemplo.
	KI-022	Investigación en "Alfabetización en Salud Digital Crítica": Evaluar cómo los pacientes hombres filtran la información que encuentran en redes sociales. Políticas de Decisión Compartida: Implementar protocolos donde el médico no "ordene", sino que el paciente elija basándose en información comprensible sobre secuelas. Medición de la Alfabetización: No solo medir si el paciente "recibió" la información, sino si fue capaz de actuar con ella (alfabetización operativa).
	KI-032	To strengthen health literacy, particular attention should be given to vulnerable populations, who are disproportionately affected by limited health literacy due to social, economic, educational, cultural or age-related factors. Health literacy should be fixed as a structural priority in health policies and healthcare systems, with a strong focus on equity and inclusion. This requires moving beyond one-size-fits-all approaches and ensuring that health information, services and care pathways are understandable, accessible and relevant for people with different needs, backgrounds and capacities. At the same time, there is a clear need to invest more in social innovation and people-centred solutions, developing interventions that are co-designed with the communities they aim to serve. Research and innovation should actively involve patients, caregivers and vulnerable groups in the design, implementation and evaluation of health literacy initiatives, ensuring that solutions reflect real-life needs and preferences. Priorities for evaluation and research include identifying unmet needs, assessing the effectiveness of tailored interventions and understanding how participatory approaches can improve trust, engagement and health outcomes. Strengthening international collaboration and sharing successful co-creation models will be essential to reduce inequalities and improve health literacy in a sustainable and inclusive way.
	KI-036	Free testing campaigns.
	KI-042	More funding looking into the specific topics looking into health literacy, national monitoring, programs aimed at increasing health literacy embedded in various organsiations at all levels.
	KI-043	A organização de um observatório europeu de literacia em saúde permitiria monitorizar a evolução da literacia em saúde nas diferentes regiões europeias e estabelecer um baseline que serviria de referência na avaliação de projetos de literacia em saúde. Do mesmo modo, permitiria identificar as verdadeiras lacunas nesta área da literacia.
	KI-045	Efectividad de intervenciones digitales (apps, portales de paciente), con especial atención a la brecha digital Investigación en ciencia de implementación
	47	Future Actions: return to facts, fight anti democratic, greed driven health care practices, improve regulation of tech platforms, AI and social media to foster credible health information and to disencourage desinformtion.
	KI-048	Support national HL policies, strategies, action plan and alliances
	KI-050	Incluir la educacion sanitaria como asignatura curricular en los diferentes niveles formativos (primaria y secundaria) Requerir a la clase politica la inversion en educacion poblacional para la prevencion como parte del presupuesto sanitario con una clara estrategia. Promover la vocación en investigacion en la universidad

Categories	Code (KI)	Verbatim Digital health literacy
	KI-053	There is already a plethora of knowledge but the challenge that WHO also emphasizes are mostly commercial determinants of health (alcohol, tobacco, ultraprocessed foods), more should be done to limit the profits that are generated through worsening of peoples health.
	KI-054	Meer folders; meer websites voor patiëntgerichte informatie, heldere apps voor patiënten die wetenschappelijk onderbouwd zijn
	KI-055	Apoiar mais as associações de doentes
	KI-057	mais informação
	KI-058	Políticas de saúde foçadas em prevenção da doença Tempo dedicado nos meios de comunicação social Parcerias com a indústria
	KI-061	MAIS INVESTIMENTO NA SAUDE E MAIS PROGRAMAS DE INCENTIVOS E CUIDADOS EM GERAL
	KI-062	Mais informações sobre as prioridades e medidas a tomar sobre literacia em saude sobre cancro prostata e mais rastreios.
	65	Criar mecanismos formais de acompanhamento e avaliação contínua
	KI-067	Criação de guidelines nacionais para prevenção, tratamento, seguimento e acompanhamento dos sobreviventes de cancro da próstata.
	KI-069	O programa de rastreio organizado do cancro da próstata deve ser priorizado. Numa perspectiva oportunistica, esta medida poderia ser complementada pela obrigatoriedade de testar o PSA no perfil de análises pedidas pela Saúde ocupacional (em homens acima dos 50 anos). As 4 grandes doenças crónicas do nosso tempo, inc. o cancro e suas medidas preventivas deveriam ser endereçadas no programa de ciencias da natureza no 3º ciclo do ensino básico de uma forma estruturada e contínua.
	KI-070	comunicação social
	KI-073	Educación sanitaria, la autoresponsabilidad a la hora de prevenir como de enfermar.
	KI-077	Dostupnost besplatnih i provjerenih informacija u javnim medijima te digitalnim kanalima. Edukacija građana kroz obrazovni sustav. Upućivanje zdravstvenih djelatnika na provjerene informacije prilagođene laicima npr. spomenuti portal HeMED.hr
	KI-079	Investimento nos atuais projetos de literacia, em detrimento de pequenos investimentos em novos projetos. Investimento na divulgação e ações de proximidade com a população. A literacia não é algo que se cumpra num momento isolado. Exige ações ao longo do tempo, reforçadas periodicamente.
	KI-086	Najveći naglasak za jačanje zdravstvene pismenosti stavio bih na: (1) podršku zdravstvenoj pismenosti kroz pomoć zakonodavca, (2) obrazovanje i osnaživanje građana/pacijenata kroz cijeli životni ciklus i (3) prilagodbu zdravstvenih sustava i digitalnih alata različitim razinama pismenosti.
	KI-091	Fromación continua con charlas, videos, webinars...que sean realistas pero no una amenaza
	KI-092	Een expertisecentrum rond (digitale) gezondheidsvaardigheden zoals Pharos waarbij inzetten op gezondheidsvaardigheden een gezondheidsdoelstelling is; Betere samenwerking, kennisdeling tussen verschillende expertisecentra en organisaties; Inzetten op het herkennen van lage gezondheidsvaardigheden bij professionals (via opleiding); Patiëntenparticipatie; Cultuursensitieve aanpak;
	KI-096	Politicas específicas de alfabetización en salud y no solo a nivel sanitario sino tambien educativo y social. Que el contexto sea favorable, entornos/organizaciones alfabetizadas en salud, asegurando que la información sea accesible, comprensible y orientada a la acción y que los profesionales esten formados para Alfabetizar en salud (ahora mismo se ven incapaces). Metodología de acción-participación donde el paciente sea protagonista y participe en todo el proceso, desde el establecimiento de politicas hasta elaboración de materiales educativos. Sellos de calidad en redes sociales, aplicaciones móviles, etc que aseguren que

Categories	Code (KI)	Verbatim Digital health literacy
		la información es confiable. Desarrollo de herramientas especificas de AS, como para el cáncer de prostata, que no se limiten a evaluar la AS funcional sino que abarquen la dimensión más aplicada de la AS. Impacto de la IA en la AS.
	KI-104	rond digitale gezondheidsvaardigheden: correcte gezondheidsinformatie en gebruik van AI.
	KI-105	Meer educatie in scholen over het menselijk lichaam, maar ook breder durven te trekken met sociale en psychologische impact op de gezondheid. Financiëringsmodellen van praktijkverpleegkundigen in zelfstandige praktijken herbekijken, zodat het ook makkelijker en in een goed kader zit om verpleegkundige aan te nemen in zelfstandige praktijken. Dit zijn ook profielen die veel kunnen opnemen.
	KI-106	Implementation of AI and molecular oncology.
	KI-113	Internet y redes
	KI-069	O programa de rastreio organizado do cancro da próstata deve ser priorizado. Numa perspectiva oportunistica, esta medida poderia ser complementada pela obrigatoriedade de testar o PSA no perfil de análises pedidas pela Saúde ocupacional (em homens acima dos 50 anos). As 4 grandes doenças crónicas do nosso tempo, inc. o cancro e suas medidas preventivas deveriam ser endereçadas no programa de ciencias da natureza no 3º ciclo do ensino básico de uma forma estruturada e contínua.
	KI-070	comunicação social
	KI-073	Educación sanitaria, la autoresponsabilidad a la hora de prevenir como de enfermar.
	KI-077	Dostupnost besplatnih i provjerenih informacija u javnim medijima te digitalnim kanalima. Edukacija građana kroz obrazovni sustav. Upućivanje zdravstvenih djelatnika na provjerene informacije prilagođene laicima npr. spomenuti portal HeMED.hr
	KI-079	Investimento nos atuais projetos de literacia, em detrimento de pequenos investimentos em novos projetos. Investimento na divulgação e ações de proximidade com a população. A literacia não é algo que se cumpra num momento isolado. Exige ações ao longo do tempo, reforçadas periodicamente.
	KI-086	Najveći naglasak za jačanje zdravstvene pismenosti stavio bih na: (1) podršku zdravstvenoj pismenosti kroz pomoć zakonodavca, (2) obrazovanje i osnaživanje građana/pacijenata kroz cijeli životni ciklus i (3) prilagodbu zdravstvenih sustava i digitalnih alata različitim razinama pismenosti.
	KI-091	Fromación continua con charlas, videos, webinars...que sean realistas pero no una amenaza
	KI-092	Een expertisecentrum rond (digitale) gezondheidsvaardigheden zoals Pharos waarbij inzetten op gezondheidsvaardigheden een gezondheidsdoelstelling is; Betere samenwerking, kennisdeling tussen verschillende expertisecentra en organisaties; Inzetten op het herkennen van lage gezondheidsvaardigheden bij professionals (via opleiding); Patiëntenparticipatie; Cultuursensitieve aanpak;
	KI-096	Politicas específicas de alfabetización en salud y no solo a nivel sanitario sino tambien educativo y social. Que el contexto sea favorable, entornos/organizaciones alfabetizadas en salud, asegurando que la información sea accesible, comprensible y orientada a la acción y que los profesionales esten formados para Alfabetizar en salud (ahora mismo se ven incapaces). Metodología de acción-participación donde el paciente sea protagonista y participe en todo el proceso, desde el establecimiento de politicas hasta elaboración de materiales educativos. Sellos de calidad en redes sociales, aplicaciones móviles, etc que aseguren que la información es confiable. Desarrollo de herramientas especificas de AS, como para el cáncer de prostata, que no se limiten a evaluar la AS funcional sino que abarquen la dimensión más aplicada de la AS. Impacto de la IA en la AS.
	KI-104	rond digitale gezondheidsvaardigheden: correcte gezondheidsinformatie en gebruik van AI.

Categories	Code (KI)	Verbatim Digital health literacy
	KI-105	Meer educatie in scholen over het menselijk lichaam, maar ook breder durven te trekken met sociale en psychologische impact op de gezondheid. Financiëringsmodellen van praktijkverpleegkundigen in zelfstandige praktijken herbekijken, zodat het ook makkelijker en in een goed kader zit om verpleegkundige aan te nemen in zelfstandige praktijken. Dit zijn ook profielen die veel kunnen opnemen.
	KI-106	Implementation of AI and molecular oncology.
	KI-113	Internet y redes

Resources and links	https://gco.iarc.fr/en https://ideahl.eu/ https://cancer-code-europe.iarc.who.int/ https://uncan.eu/a-role-for-patients-and-citizens/ https://cancerpatientseurope.org/intervene/ https://www.escueladesaludmurcia.es/escuelasalud/mantenersalud/videos_urologia.jsf https://www.alfabetizacionsalud.com/ https://prostatecanceruk.org/risk-checker https://commission.europa.eu/topics/public-health/european-health-union/cancer-plan-europe_es https://curtainproject.eu/ https://aicib.pt/2025/07/01/ja-esta-disponivel-a-2a-edicao-do-guia-de-recursos-para-a-pessoa-com-doenca-oncologica-e-seus-cuidadores/ https://www.escueladepacientes.es/cancer/cancermama/guias-cancer-de-mama https://www.escueladepacientes.es/cancer/cancer-colorrectal/guias-cancer-colorrectal https://www.saludcastillayleon.es/escueladepacientes/es/enfermedades/cancer https://www.astursalud.es/categorias/-/categorias/profesionales/01000practica-clinica/03000programas-de-deteccion-y-prevencion/02000programas-de-deteccion-precoz-cancer https://www.sciencedirect.com/topics/medicine-and-dentistry/health-belief-model https://www.australiancancerplan.gov.au/actions/2.2.2 https://consultations.health.gov.au/national-preventive-health-taskforce/national-health-literacy-strategy-framework-consul/ http://www.gezondheidsvaardigheden.nl https://pure.amsterdamumc.nl/en/persons/mirjam-fransen/ https://www.zagreb.info/vijesti/podizanje-svijesti-bolesti-prvi-sveobuhvatni-prirucnik-bolesnike-s-rakom-prostate/96847/ https://www.alfabetizacionsalud.com/quienes-somos/ https://hemed.hr/ https://www.hdbrp.hr/wp-content/uploads/2022/08/Rak-prostate-prirucnik-za-bolesnike.pdf https://saludextremadura.ses.es/web/ https://www.educarex.es/programas-educativos/educacion-para-la-salud.html https://canalsalut.gencat.cat/ca/salut-a-z/c/cancer/tipus https://www.escuelacantabradesalud.es/web/escuela-cantabra-de-salud/cancer-de-mama https://www.comunidad.madrid/servicios/salud/cancer https://www.osakidetza.euskadi.eus/enfermedades-cancer/webosk00-oskcon/es/ https://einasalut.caib.es/web/paciente-activo/cuidate-con-tu-enfermedad https://www.sanidad.gob.es/areas/promocionPrevencion/home.htm https://symptomnavi.ch/de/

Annex 8. Verbatim quotes – Quality and comprehension of information

Category	Code (KI)	Verbatim Quality and comprehension of information
Tools and Strategies		
	KI-005	Conozco herramientas que se utilizan para la alfabetización en salud, como los talleres de la Escuela de Pacientes y sus talleres de cáncer de mama y de Ostomías, por un lado, además de la difusión que se hace desde el registro de cáncer de Granada y d e los programa que hace Joan Carles March en TV y en podcasts para alfabetizar a la población al tratar temas de cancer, entre los que hay programas de cancer de próstata. También hemos colaborado con **cancer de próstata en una acción de montaña** con pacientes con cáncer d próstata para hacer alfabetización sanitaria
	KI-010	Páginas webs institucionales: Astursalud. Se dispone de material informativo vinculado a los cribados de cáncer de mama, colorrectal y cérvix. Nada específico en cáncer de próstata https://www.astursalud.es/categorias/-/categorias/profesionales/01000practica-clinica/03000programas-de-deteccion-y-prevencion/02000programas-de-deteccion-precoz-cancer
	KI-021	Conozco algunas herramientas por que pertenezco al sector y estamos en proyectos de cooperación. A nivel de usuarios no se conocen.
	KI-023	In Sweden we do not regularly use any tools, but the concept and tools have been translated into Swedish. We do not asses health literacy in Swedish cancer care, but several studies incorporate the concept.
	KI-038	Páginas webs de Escuelas de Pacientes: Programa de Cáncer de mama en la Escuela de Pacientes de Canarias. Programa del **Aula de Pacientes Dr. Negrín** (cancer)
	KI-083	la herramienta de "teach-back", "plain language" y "health literacy questionnaire"
	KI-110	Conoozxo TUCUVI Tu Cuidador Virtual. Pero no sé si es una herramienta de alfabetización de salud
Good practices and Initiatives	KI-005	Una actividad digna de ser calificada de valoración de buenas prácticas es el concurso de alfabetización sanitaria que hacía la escuela de pacientes y la escuela andaluza de salud pública donde se premiaban las buenas prácticas en intervención en alfabetización sanitaria Se premiaban por un lado las actividades de equipo, además de las de ámbito tecnológico. Se hacía una selección d ellas más relevantes, para luego ser presentadas públicamente las 5 mejores y ser votadas por un jurado. También hemos realizado Coloquios de alfabetización sanitaria como fórmula para trabajar diversos aspectos como: - Alfabetización: una de las claves para mejoras resultados en la atención al paciente crónico - No queremos tener otro susto. Cómo evitar los segundos eventos.
	kI-013	National Health Literacy Strategy Framework consultation Austtralia https://consultations.health.gov.au/national-preventive-health-taskforce/national-health-literacy-strategy-framework-consul/
	KI-013	Especificamente en relacion con la atención oncológica no sólo la alfabetización juega un rol importante sino también las creencias en general. El **health belief model** https://www.sciencedirect.com/topics/medicine-and-dentistry/health-belief-model puede resultar util aqui´, tambien cuestiones de sociologia de la salud (creencias, mitos, imaginarios en torno a la salud)
	kI-023	The Youth Barometer surveys the opinions of young people (15-25 years old) every year and they have involved health literacy questions, which indicates an interest in including the concept in the work of the Public Health Authority.
	KI-075	Red española de alfabetización para la salud
	KI-039	Un ejemplo exitoso es la campaña Choosing Wisely, que fomenta decisiones informadas mediante materiales claros para pacientes y profesionales.

Category	Code (KI)	Verbatim Quality and comprehension of information
Gaps and Challenges	KI-004	En general, una de las principales lagunas en alfabetización en salud es que la información existe, pero no siempre es comprensible, contextualizada ni útil para tomar decisiones reales. A menudo se transmite de forma excesivamente técnica, centrada en la enfermedad y no en lo que la persona necesita saber para manejar su situación cotidiana. En la atención oncológica, una necesidad no cubierta es el acompañamiento informativo a lo largo de todo el proceso, no solo en el momento del diagnóstico. Muchas personas tienen dificultades para entender opciones de tratamiento, efectos secundarios, impacto en la calidad de vida o qué apoyos existen, especialmente cuando el proceso se alarga o se cronifica. En conjunto, el reto principal es pasar de informar a capacitar, incorporando lenguaje claro, tiempo, apoyo emocional y espacios donde las personas puedan preguntar, reflexionar y decidir con seguridad.
	KI-005	Escasa adaptación cultural y lingüística de las herramientas existentes. Insuficiente atención a población vulnerable: • Personas mayores • Migrantes y minorías étnicas • Personas con bajo nivel educativo • Personas con discapacidad cognitiva o sensorial Falta de enfoques interseccionales (edad + género + nivel socioeconómico). Aumento de la infodemia y noticias falsas en salud
	KI-007	Health literacy responsiveness of organizations and health professionals as well as health systems are generally very low, which is a main barrier for its implementation in general but also in specific fields of diseases.
	KI-009	there remains a view that health literacy is more about health information, numerical and reading literacy rather than the ability o understand and apply health information. Concepts such as patient activation- due to the implementation a number of years ago of a national program are far more dominated- though the difference between health literacy and activation are an open debate
	KI-011	• Brecha de alfabetización y digital: materiales poco accesibles para personas mayores, baja escolarización, entornos vulnerables; faltan alternativas no digitales y apoyos (mediadores/navegadores). • Información poco "accionable": mucho contenido, pero poca guía práctica sobre qué significa, qué preguntar y qué pasos seguir; escasean formatos en lenguaje claro, lectura fácil, multilingüe. • Comunicación del riesgo insuficiente (muy crítico en próstata): dificultades para explicar probabilidades, falsos positivos/negativos, y sobrediagnóstico/sobretratamiento en torno a PSA. • Decisión compartida poco implantada: falta de ayudas a la decisión integradas en consulta (option grids, checklists de preguntas) y formación en comunicación clara. • Desinformación (redes/IA): ruido informativo y fuentes no fiables sin estrategias sólidas de verificación y derivación a recursos seguros. • Paliativos tardíos y poco planificados: tabú y falta de materiales/itinerarios para planificación anticipada y apoyo a cuidadores. • Poca co-creación y evaluación: materiales no siempre diseñados/testados con pacientes; falta medir impacto (comprensión, elección informada, PREMs/PROMs y equidad).
	KI-033	Las informaciones claras, explicitas, detalladas en lenguaje no clínico para los pacientes con decisiones bien informadas y sinceramente compartidas.
	KI-083	la complejidad del lenguaje, falta de tiempo en la consulta, hablar de temas "tabus" de la masculinidad y la desigualdad digital.
	KI-089	En general, la inclusión de alfabetización en salud en la educación formal.

Category	Code (KI)	Verbatim Quality and comprehension of information
	KI-104	over het algemeen zijn de meeste brochures niet in eenvoudig taalgebruik, wordt er niet altijd met herkenbaar beeldmateriaal gewerkt, ..
Recommendations	KI-018	Zie boven. Richten op health literacy responsiveness.
	KI-021	Llevarla la información donde normalmente no se busca. Si ofrecemos información de salud y alfabetización en salud en lugares de salud, es muy obvio. Normalmente se acude a esos lugares tras la detección de una patología, pero no de forma previa
	KI-063	Comunicação mais acessível para todos, tendo em conta a cultural, contexto socio-económico, entre outros. Criar ferramentas atrativas para a população. Aumentar o número de pessoas credíveis a transmitirem informação.
	KI-082	Mandate health-literate communication standards in public healthcare. Co-design materials with migrants, older adults, low-literacy populations, people with disabilities and minority communities.
	KI-083	Institucionalización del "plain language". exigir por ley que todo consentimiento informado y material de cribado esté redactado en lenguaje sencillo y validado por pacientes
	KI-084	Participatiegraad verhogen bij bevolkingsonderzoek
	KI-100	Que esta encuesta debe incluir pacientes y ciudadanos en este proceso de exploración y co-creaccion
	KI-107	Diría que una prioridad es la incorporación real de los pacientes en el desarrollo de iniciativas de alfabetización. Para poder hablar de co-diseño.
	KI-112	Estandarización de la información dada a los pacientes (especialmente escrita), para que cumpla estándares de "lectura fácil" y accesibilidad cognitiva.
Resources and links	https://www.astursalud.es/categorias/-/categorias/profesionales/01000practica-clinica/03000programas-de-deteccion-y-prevencion/02000programas-de-deteccion-precoz-cancer https://www.alfabetizacionsalud.com/quienes-somos/ https://www3.gobiernodecanarias.org/noticias/el-hospital-doctor-negrin-pone-en-marcha-una-nueva-edicion-del-aula-de-pacientes/ https://www.choosingwisely.org/ https://www.sciencedirect.com/topics/medicine-and-dentistry/health-belief-model https://consultations.health.gov.au/national-preventive-health-taskforce/national-health-literacy-strategy-framework-consul/	

Annex 9. Verbatim quotes – Clinical communication and shared decisions

Categories	Code (KI)	Verbatim Clinical communication and shared decisions
Tools and Strategies	KI-009	yes- England- policy such as personalised care,https://www.england.nhs.uk/eolc/personalised-care/ integrated care and cancer care, shared decision making etc all have operating models that recognise the importance of empowering patients to be at the heart of decision making. Health literacy though is not the core concept and concepts such as activation, self efficacy are much more widely used as measures. NHS England produce a guide on evaluating these areas https://www.england.nhs.uk/personalisedcare/supported-self-management/health-system-support-framework-for-supported-self-management/
	KI-039	Sí, existen herramientas y estrategias para promover la alfabetización en salud, como programas de educación sanitaria institucional, campañas de comunicación pública y recursos digitales orientados a mejorar la comprensión de la información en salud. En el ámbito del cáncer, estas estrategias se concretan en iniciativas de educación al paciente y apoyo a la toma de decisiones compartida.
	KI-058	Liga portuguesa contra o cancro Sociedades Médicas - SPO, APU, SPUO
	KI-075	No conozco ninguna de alfabetización, pero si algunas herramientas de ayuda a la toma de decisiones para pacientes con cáncer de próstata en España y en otros países.
	KI-109	realmente no hay herramientas fuera de mínima comunicación por médicos
Good practices and Initiatives	KI-003	Protocolo de toma de decisiones compartidas para personas con enfermedad renal crónica en el área 3 de salud del Principado de Asturias. Toma de decisiones compartidas de Cataluña https://decisionscompartides.gencat.cat/es/decidir-sobre/atencio-final-vida/
	kI-011	Knowing Your Options (https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options): permite a los pacientes recién diagnosticados, que se enfrentan a varias opciones de tratamiento diferentes, ingresar sus propios parámetros personales de cáncer, como PSA y otros resultados de pruebas, en un enlace web seguro que analiza sus datos y establece su gama completa de opciones, con riesgos y beneficios específicos para esa persona. Código Europeo de Prácticas en el Oncología (https://www.europeancancer.org/content/european-code-of-cancer-practice.html) Mac Millan Cancer Support (https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions): ayuda a comprender opciones de tratamiento.
	KI-032	Health literacy guides and good-practice frameworks developed by the Council of Europe - https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75 highlight the importance of providing clear health information, enhancing access to reliable content and promoting shared decision-making within health systems, which are essential components for informed prostate cancer screening decisions, treatment choices and end-of-life care discussions. The European Cancer Organisation publicated the 'Cancer literacy – Informing patients and implementing shared decision making' https://www.sciencedirect.com/science/article/abs/pii/S2213538322000546?dgcid=author an article in the Journal of Cancer Policy. This work includes recommendations that could be adapted to prostate cancer contexts to promote better health literacy, patient engagement and shared decision-making.
	KI-047	**Share to Care (Germany):** El programa **SHARE TO CARE** apoya a las personas en la toma de decisiones médicas junto con sus médicos y enfermeras, decisiones adaptadas a sus necesidades y situación vital. El programa integral consta de varios componentes y promueve la toma de decisiones compartida. https://share-to-care.de/
	KI-009	no- the focus has been on shared decision making and withing that supporting the patient to participate in this process. Guidance on developing tools are at https://www.nice.org.uk/corporate/ecd8

Categories	Code (KI)	Verbatim Clinical communication and shared decisions
	KI-096	La sustentada por la OMS para la COVID-19 tanto a nivel nacional como internacional. Para la toma de decisiones informadas la que se realiza en la unidad del Hospital Universitario Punta de Europa con los enfermos renales para decidir que tipo de tratamiento de diálisis.
Gaps and Challenges	KI-006	el Lo primero de todo, trabajar el propio concepto de alfabetización, ya que alfabetizar no solo es dar información, es trabajar la comprensión, la valoración crítica, la comparación de opciones, así como la toma de decisiones coherente con los valores. Además, es precioso institucionalizar la alfabetización en salud como parte de la atención estándar.
	KI-008	Hacer partícipes a los pacientes en la toma de decisiones en los procesos oncológicos.
	KI-027	Falsos mitos, desconocimiento sobre los riesgos reales.
	KI-031	Incluso en otros tipos de tumores (por ejemplo, el cáncer de mama) se han identificado desafíos relacionados con la alfabetización en salud: el estrés emocional, las ideas erróneas y la baja capacidad para comprender información compleja pueden dificultar la participación en programas de cribado o la toma de decisiones informadas sobre el tratamiento. Ni el paciente ni su familia reciben una orientación adecuada, y en la consulta no hay suficiente tiempo para ello.
	KI-039	Las principales lagunas en alfabetización en salud incluyen el acceso desigual a información comprensible, la falta de materiales adaptados cultural y lingüísticamente, y la escasa formación de profesionales en comunicación efectiva. En oncología, y específicamente en cáncer de próstata, persisten retos en apoyar la toma de decisiones informada, la comprensión de riesgos y beneficios de cribado y tratamiento, y la educación sobre cuidados paliativos.
	KI-063	Informação que seja acessível à população em geral, muitas vezes a informação é pouco atrativa e percetível, o que leva ao aumento da crença em diversos mitos. Também a comunicação com o médico nem sempre permite uma abordagem que promova a tomada de decisão conjunta.
	KI-082	There are inequalities in understanding and access. Health literacy isn't evenly distributed. There can be information overload at diagnosis: patients receive huge volumes of information at once, often with complex language and statistics, with little time to absorb, reflect, and ask questions. True shared decision-making is inconsistently implemented. Some consultations are still clinician-led, the risks and benefits are not always explained clearly, probabilities can be poorly communicated, and patient values aren't always explored.
	KI-088	Una de las principales lagunas/retos es cómo se comunica la información. El gran reto es adaptar la información al nivel de alfabetización de cada usuario al que va destinada.
	KI-096	el reto en general está en la comunicación con el paciente, en el uso de las nuevas tecnologías y la IA y en el nivel crítico de la AS. En el caso concreto, bajo nivel de conocimiento en los hombres lo que dificulta prevención, diagnóstico temprano (Cribado de Cáncer de próstata con prueba de PSA) y toma de decisiones informadas.
Recommendations	KI-066	Acções de divulgação híbridas, criando eventos com doentes, que sejam preparados através de novos meios de comunicação, para o evento seja uma âncora no qual a divulgação de informação gire em redor.
	KI-075	Desarrollo de herramientas de ayuda a la toma de decisiones sobre tratamiento
	KI-093	Que los médicos conozcan los daños a largo plazo de las terapias implementadas
	KI-112	Incentivar que los médicos de familia "prescriban" enlaces a recursos como las escuelas de usuarios y pacientes (tal como la Escuela Gallega de Salud para Ciudadanos), y que podrían consultarse mucho mas.

Categories	Code (KI)	Verbatim Clinical communication and shared decisions
Resources and Links		https://decisionscompartides.gencat.cat/es/decidir-sobre/atencio-final-vida/ https://www.england.nhs.uk/eolc/personalised-care/ https://www.england.nhs.uk/personalisedcare/supported-self-management/health-system-support-framework-for-supported-self-management/ https://www.nice.org.uk/corporate/ecd8 https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75 https://www.sciencedirect.com/science/article/abs/pii/S2213538322000546?dgcid=author https://www.contraelcancer.es/es/todo-sobre-cancer/tipos-cancer/cancer-prostata https://www.europeancancer.org/content/european-code-of-cancer-practice.html https://prostatecanceruk.org/risk-checker https://www.canceralliance.co.uk/professionals/prostate-cancer-know-your-options https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/making-treatment-decisions https://www.madrid.org/bvirtual/BVCM017405.pdf https://pubmed.ncbi.nlm.nih.gov/33568208/ https://www.krebshilfe.de/informieren/ueber-krebs/

Annex 10. Verbatim quotes – Prostate cancer screening

Category	Code (KI)	Verbatim Prostate cancer screening
Tools and Strategies	KI-019	Técnicas pioneras no invasivas para Cáncer de próstata en el Hospital de Cabueñes
	KI-018	Zie www.gezondheidsvaardigheden.nl. In het PGUIDE project (getrokken door Erasmus MC) werken we aan tools om mensen bewust te maken van het risico op prostaatkanker en hen te ondersteunen in de beslissing om wel of geen screeningstest te doen. Daarnaast hebben we in het kader van bestaande screeningsprogramma's verschillende interventies ontwikkeld om de health literacy responsiveness te verbeteren. Zie https://pure.amsterdamumc.nl/en/persons/mirjam-fransen/. In een huidig project 'INSIDERS' richten we ons op het inzetten van mHealth voor het verbeteren van bereik en geinformeerde besluitvorming in verschillende vormen van kankerscreening.
	KI-040	General Hospital St. Pölten. Starting national prostate screening program this year After we are done with Austrian screening program, we should compare the results
	Ki-053	In 2025 Government of Slovenia has adopted National Health Literacy Strategy 2025 - 2035 as well as the accompanying Action plan 2025 - 2027, both include further promotion of cancer screening programmes already in place as well as forseen ones (prostate and lung cancer).
Good practices and Initiatives	KI-026	La campaña realizada en su momento para el abordaje del VIH combinando campañas de información, acceso a tratamiento y pruebas diagnósticas.
	Ki-011	• Risk checker UK: https://prostatecanceruk.org/risk-checker: evaluador de riesgo. • PSA Test (https://www.nhs.uk/tests-and-treatments/psa-test/): análisis de sangre que ayuda a detectar afecciones de la próstata, como cáncer de próstata o agrandamiento de la próstata. • User-testing an interactive option grid decision aid for prostate cancer screening: lessons to improve usability: https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/
	KI-019	Proyecto Cassandra para Cáncer de pulmón en el Hospital San Agustín
	KI-031	En la República Checa, desde enero de 2024, se ha lanzado un nuevo programa de cribado del cáncer de próstata, que hasta ahora es uno de los primeros de este tipo en la UE. El programa está dirigido a hombres de entre 50 y 69 años y tiene como objetivo aumentar la proporción de hombres en los que se detecta el cáncer de próstata en una etapa clínica temprana, lo que mejora significativamente las posibilidades de un tratamiento exitoso. El programa se organiza como parte de la revisión preventiva habitual con el médico de atención primaria.
	KI-033	WHO: Implantación del Plan Europeo de la Lucha contra el Cáncer de 22 septiembre 2022. Pidió a los estados miembros nuevos cribados entre ellos el de cáncer de próstata
	KI-044	Ministry of Health and Population (MoHP) Egypt Runs public health campaigns on non-communicable diseases and cancer awareness (mostly breast cancer) that can be adapted by large-scale media campaigns targeting men for early detection, PSA screening
Gaps and Challenges	KI-010	la necesidad es disponer de una prueba de cribado en cáncer de próstata que cumpla los requisitos exigibles de sensibilidad y especificidad. En este momento no existe. También es un reto aumentar el acceso a los tratamientos menos lesivos y más seguros disponibles en el cáncer de próstata

Category	Code (KI)	Verbatim Prostate cancer screening
	KI-073	Creo que hay un gran reto con el cáncer de colon, así como en el cáncer de próstata en relación a los protocolos de cribado si los comparamos con el de cáncer de mama en la Comunidad autónoma de Canarias.
	KI-075	En el cribado de cáncer de próstata con PSA: los hombres saben que existe pero les falta información clara de si esta recomendado, en que condiciones, edad…
	KI-110	La mayor necesidad es el conocimiento de cuándo y cómo debe hacerse el cribado No está estructurado
	KI-112	La ausencia de algoritmos claros de manejo de la determinación de PSA, que tiene lugar en el cribado oportunista del cáncer de próstata, ha llevado a una gran heterogeneidad de actuaciones, que han acarreado sobrecarga de vías clínicas no preparadas para la derivación de hombres asintomáticos, exceso de biopsias, gran cantidad de falsos positivos, y sobrediagnóstico y sobretratamiento de lesiones indolentes. Todo ello con altos costes asociados. En este escenario, existe una evidente necesidad de información clara y rigurosa a los hombres acerca del cáncer de próstata y lo que cabe esperar en el cribado
Recommendations	KI-010	Políticas poblacionales de información. Investigación en marcadores de cáncer que puedan ser usados como prueba de detección en un cribado poblacional
	KI-036	Educational campaigns by medical professionals and primary care physicians about PSA screening in adults. I think online and social media campaigns on Facebook, Instagram, and TikTok can be highly impactful on medical education and improve participation in screening programs
	KI-041	La evidencia científica sobre el cribado de cáncer de próstata (CP) es controvertida, pues si bien reduce la detección de tumores avanzados y aumenta la detección de cánceres localizados, pero no ha demostrado una reducción clara y consistente de la mortalidad general o por CP en grandes estudios, debido a los daños del sobrediagnóstico y sobretratamiento (que incluyen cánceres que nunca se habrían manifestado). La mayoría de las guías recomiendan discutir el cribado (PSA y tacto rectal) con hombres entre 55-69 años o antes si hay factores de riesgo como raza negra o antecedentes familiares, informando claramente sobre beneficios y riesgos, dejando la decisión final al paciente, ya que no hay una recomendación universal para el cribado poblacional general. Nuevas tecnologías como pruebas genéticas (como para mutaciones BRCA) podrían mejorar la estratificación del riesgo, pero actualmente no hay consenso para un cribado poblacional universal debido a los daños, pero la detección precoz activa puede ser beneficiosa en grupos de riesgo, siempre tras una conversación exhaustiva sobre riesgos y beneficios con el paciente para una decisión informada.
	KI-044	Digitally, patients rely heavily on social media (Facebook, YouTube) and individual physician or hospital pages. However, no official digital platforms are providing evidence-based, Arabic-language tools for prostate cancer screening, treatment decision making, or palliative care.
	KI-060	Debería hacerse campañas de concienciación sobre la importancia del cribado precoz y de llevar estilos de vida saludables para reducir el riesgo de su aparición
	KI-084	Detección de cáncer de colon mediante carta o médico de cabecera con prueba iFOBT. Standaard PSA screening via de huisarts in het bloed vanaf een bepaalde leeftijd.
	KI-092	Ik vermoed ook dat er wel wat taboe rust op screening voor prostaatkanker, wat een extra drempel en uitdaging is. Niet elke zorgverlener is vertrouwd met wat gezondheidsvaardigheden zijn.
	KI-110	Conocer la realidad de oportunidades de acceso a los diagnósticos y tratamientos en la realidad de cada país.
	KI-113	Insistir en la evidencia científica del screening de ca próstata

Category	Code (KI)	Verbatim Prostate cancer screening
Resources and Links		https://prostatecanceruk.org/risk-checker https://www.nhs.uk/tests-and-treatments/psa-test/ https://preventiemethodieken.be/vertelkaartjes-verloop-bevolkingsonderzoek-baarmoederhalskanker www.gezondheidsvaardigheden.nl https://pure.amsterdamumc.nl/en/persons/mirjam-fransen/ https://www.g-ba.de/service/versicherteninformationen/frueherkennungsuntersuchungen/ https://pmc.ncbi.nlm.nih.gov/articles/PMC6538002/

Annex 11. Verbatim quotes – Evaluation and Research

Category	Code (KI)	Verbatim Evaluation and Research
Tools and Strategies	KI-047	Two information offers in Germany are the Cancer Information Service (https://www.krebsinformationsdienst.de/) at the German Center of Cancer Research and the website of the German Cancer Aid https://www.krebshilfe.de/informieren/ueber-krebs/
	KI-013	Estrategias conozco la del proyecto IDEAHL.
	kI-87	Desde la Universidad de Cádiz, en colaboración con otros profesionales de diversas instituciones, estamos llevando a cabo un proyecto de mHealth para fomentar la alfabetización en salud y la autogestión de los pacientes con insuficiencia cardíaca. Se ha codiseñado una app de salud dirigida a estos pacientes. Actualmente estamos en la fase de validación de la herramienta en el ámbito clínico.
	KI-088	Por otro lado, MiCardiApp es otra iniciativa relevante. Se trata de un proyecto financiado por el Instituto de Salud Carlos III, cuyo objetivo es validar clínicamente una app, orientada a mejorar la alfabetización en salud y la autogestión de la enfermedad en pacientes con insuficiencia cardíaca.
Good practices and Initiatives	KI-007	Policy Guide of M-POHL (https://m-pohl.net/ResultsEVPOP) Digital and navigational health literacy assessment in cancer survivors: using Swiss HLS19 Instruments
	KI-064	The EUPROMS (Europa Uomo Patient Reported Outcome Study) study in cancer de prostate
Gaps and Challenges	KI-005	Dificultad para evaluar la credibilidad de la información en línea. Instrumentos de medición limitados, a menudo centrados solo en lectura y comprensión, no en toma de decisiones. Falta de indicadores claros para su seguimiento y evaluación. Escasez de estudios longitudinales. Dificultad para medir impacto real en resultados de salud y equidad.
Recommendations	KI-004	Es clave evaluar no solo el nivel de conocimiento de la población, sino su capacidad real para comprender, decidir y actuar. La investigación debería centrarse en medir la comprensión práctica, el impacto en la calidad de vida y la reducción de desigualdades, especialmente en poblaciones vulnerables. Otra prioridad es invertir en investigación aplicada, que analice qué formatos, mensajes y entornos funcionan mejor (presencial, digital, comunitario), y que implique a pacientes y ciudadanía en el diseño y evaluación de las intervenciones.
	KI-006	Evaluar impacto real y equidad (comprensión, elección informada, PREMs/PROMs, conflicto decisional), desagregado por grupos vulnerables. Marco e indicadores comunes y financiación estable para escalar buenas prácticas, incluyendo criterios de calidad y transparencia (también para IA).
	KI-007	The value of health literacy should be made clear and national strategies and action plans to promote health literacy should be put in place - including regular monitoring of health literacy of the population, implementation measures in practice, health literacy in early education as well as professional education etc.

Category	Code (KI)	Verbatim Evaluation and Research
	kI-015	The use of interactive person virtual programs. Evaluating the reach of programs and this reach is accomplished. https://selfmanagementresource.com/resources/evaluation-tools/
	kI-026	Además, considero indispensable que conozcan las fuentes de información más fiables estableciendo páginas oficiales que contengan listados de "sitios" donde consultar información en función de los temas a abordar. Para evaluación: impacto de campañas, indicadores validados para medir la alfabetización de la salud a nivel europeo, determinar retorno de inversión en programas de alfabetización para realizar los ajustes oportunos en caso necesario
	kI-40	Prostate cancer marker research
	KI-46	Uključite ljude u projekte koji se bave rakom. Potrebno je jasno i strukturirano praćenje ishoda, aktivno sudjelovanje u radnim skupinama, izrada evidence based NICE i sličnih javnozdravstvenih intervencija.
	KI-81	Financiranje primjera dobrih praksi, provjerenih s evidence based dokazima ili nice smjernicama. Ne ekspirementiranje svojih ideja na općoj populaciji
	KI-100	Create a national strategy and action plans with specific measures, which must be evaluated, not in general terms, so if it's done well, it's okay, and if it's not done, it doesn't matter.
	KI-112	Desarrollar Indicadores que evalúen los sistemas de salud no solo por resultados clínicos, sino por el grado en que el paciente comprendió la información suministrada, las opciones diagnósticas/terapéuticas, y sus procesos patológicos. Impacto de la alfabetización en salud en el gasto público. Cuantificar efectos que cabría esperar: menor uso de urgencias, mejor adherencia a los tratamientos.
Resources and Links		https://www.nice.org.uk/what-nice-does/standards-and-indicators https://www.europa-uomo.org/who-we-are/quality-of-life-2/the-euproms-study/ https://selfmanagementresource.com/resources/evaluation-tools/ https://academic.oup.com/eurpub/article/35/Supplement_4/ckaf161.267/8303201?login=false https://pubmed.ncbi.nlm.nih.gov/33352951/ https://www.nice.org.uk/ https://selfmanagementresource.com/resources/evaluation-tools/ https://www.krebshilfe.de/informieren/ueber-krebs/ https://www.europa-uomo.org/who-we-are/quality-of-life-2/the-euproms-study/