





# **Joint Action on Networks of Expertise**

Deliverable number, 12.1

Recommendations for effective and efficient organization and management of research efforts

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#### **LIST OF ABBREVIATIONS**

AE Affiliated Entity

BIOSISTEMAK Instituto de Investigación en Sistemas de Salud (formerly Kronikgune)

CA Competent Authority

CCC Comprehensive Cancer Center

CCI Europe European Childhood Cancer International

CCN Comprehensive Cancer Networks

CIBER Consorcio de Investigación Biomédica en Red

CIBERONC Centre for Biomedical Research in Cancer Network

COST Actions European Cooperation in Science and Technology

EAPC European Association for Palliative Care

EHDS European Health Data Space

EURTC European Organization for Research and Treatment of Cancer

ERIC European Research Infrastructure Consortium

ERICA European Rare Disease Research Coordination and Support Action consortium

ERN European Reference Network

ESMO European Society for Medical Oncology

ESSO European Society of Surgical Oncology

ESTRO European Society for Radiotherapy and Oncology

EU European Union

EU-CAYAS-NET EU Network of Youth Cancer Survivors

EURACAN European Reference Network on Rare Adult Cancers (solid tumors)

GDPR General Data Protection Regulation

GENTURIS European Reference Network on GENetic TUmour RIsk Syndromes

HE Horizon Europe

HSJD Hospital Sant Joan de Deu

ICO Instituto Catalán de Oncología

IDIVAL Fundación Instituto de Investigación Marqués de Valdecilla

INT Istituto Nazionale dei Tumori

ISCIII Instituto de Investigación Carlos III



JA Joint Action

JANE EU JOINT ACTION NETWORKS OF EXPERTISE ON CANCER

KG Kronikgune

MS Member States

NFP National Focal Points

NoEs Networks of Expertise

OECI Organization of European Cancer Institutes

OIL ONKOLOSKI INSTITUT LJUBLJANA

PAEDCAN European Reference Network for Paediatric Oncology

PANCARE Pan-European Network for Cancer of Survivors after Childhood and Adolescent

Cancer

PCE Pancreatic Cancer Europe

PHEM Pediatric Health Data Space

PRC European Palliative Care Research Centre

PROM Patient Reported Outcome Measure

RICAPPS Research Network on Chronicity, Primary Care and Prevention and Health

Promotion

SAS Servicio Andaluz de Salud

SCReN Clinical Research Units and Clinical Trials Platform

SIOPE European Society for Paediatric Oncology

STRONG-AYA Improving the Future of Adolescents and Young Adults With Cancer

TRANSLACORE Translational control in Cancer European Network

TTFF Transversal Task Force

UNCAN.eu European Initiative to UNderstand CANcer

WHO World Health Organization

WOS Web of Science

WP Work Package





## **RECIPIENTS OF THIS DOCUMENT**

EU4H-2021-JA-IBA

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.

#### **PROJECT INFORMATION**

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#### 1 EXECUTIVE SUMMARY

The overall objective of the JANE Joint Action was to establish seven Networks of Expertise (NoEs) in the cancer field by preparing everything necessary to launch them and critically evaluating existing models of current and future EU networking. These networks will foster collaboration and knowledge sharing among all EU Member States, leading to the development of guidelines and best practices, facilitating research and innovation, enhancing education and training, and ultimately improving health policy at both national and European levels.

Within the JANE work packages (WPs), a series of Transversal Task Forces (TTF) have been developed. These TTFs included cross-cutting objectives to support the WPs in relation to the NoEs, facilitating interaction and encouraging collaboration on aspects that were considered challenging for the NoEs. Specifically, there is one, WP12 or TTF1 designed to bring answers to the challenge about the integration between health care and research.

The purpose of this document is to present the results of the work done in WP12 with a set of recommendations for effective and efficient organization and management of research efforts, based on the analysis of current gaps and facilitators in the integration between health care and research and the definition of the necessary structures to carry out relevant clinical research. This document constitutes deliverable 12.1 of JANE.

The approach followed in JANE for the elaboration of this set of recommendations is based on the results of different activities, including: (1) A desktop search; (2) A systematic review of the literature; (3) Expert advice; and (4) Consultation of different sources of information.





#### STRUCTURE OF THE DOCUMENT

The content of this document is presented as follows. **Section 1** contains the executive summary. **Section 2** provides the introductory aspects of the work presented in this deliverable, introducing JANE Joint Action, the purpose of the document and its intended audience. **Section 3** describes the methodology employed to formulate the final recommendations, through the activities designed for this purpose. **Section 4** presents the state of play of the main areas explored in the work package. **Section 5** lists the main recommendations for effective and efficient organization and management of research efforts derived from the activity results. **Section 6** presents next steps on how to exploit NoEs to advance research. The report also includes **three annexes** that provide more detail on the methodology and results of the different WP12 activities





Version 0.5

#### INTRODUCTION

#### 2.1 JANE project summary

The JANE project (EU Joint Action in Networks of Expertise on Cancer, <a href="https://jane-project.eu/">https://jane-project.eu/</a>), falls within the framework of the European Union's EU4Health Program, specifically the Joint Actions (JA) which aim to foster cooperation, coordination, and knowledge-sharing among Member States in various areas of health policy and practice.

One of the flagship initiatives of Europe's Beating Cancer Plan<sup>1</sup> for ensuring high standards in cancer care is the establishment, by 2025, of an EU network linking recognized National Comprehensive Cancer Centres (CCCs) in every Member State. Additionally, this flagship has included the creation of new type of Reference Networks to be established in Europe aimed to look at specific challenging cancer conditions, which will benefit from cross-border cooperation and EU expertise. JANE is the mechanism by which this flagship will be responded through the creation of seven Networks of Expertise (NoEs) in the areas of complex and poor prognosis cancers, palliative care, survivorship, personalised primary prevention, omics, high-tech medical resources, and adolescents and young adults with cancer.

JANE project was coordinated by Instituto Nazionale Dei Tumori (INT), it started in October 2022 and involved the participation of 16 Competent Authorities, 20 Affiliated Entities and 2 Patient Associations from 16 countries all around Europe.

#### The general goals of JANE were:

- To prepare everything necessary to launch the new Networks of Expertise; from defining their mission and objectives, studying their design and working out the selection criteria for participants, to providing all items to set up calls for expressions of interest.
- To critically evaluate existing models of current and future EU networking, research infrastructures and platforms, future networking among comprehensive cancer centres, as well as technologically relevant aspects for optimal functioning of networking in general, in order to properly shape the new NoEs.

JANE has outlined and prepared these NoEs to cover these crucial areas of cancer care, bringing together the best resources available in Europe in each specific field, to support National Networks and CCCs. The results of the work done during JANE will serve as a basis for the follow-up Joint Action (JANE 2) that

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<sup>&</sup>lt;sup>1</sup> COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL Europe's Beating Cancer Plan. Available in: https://health.ec.europa.eu/system/files/2022-02/eu cancer-plan en 0.pdf





will also be coordinated by Istituto Nazionale de Tumori (INT) in Milan, and it will start in November 2024. JANE 2 will allow the launch of the seven NoEs and will provide services aiming to contribute to the development of guidelines and best practices and to facilitate research and innovation, enhance education and training, and strengthen health policies at regional, national and European levels, supporting the concept of "network of networks" between the different Member States (MSs).

Within JANE, the Work Package (WP) 12 or transversal task force (TTF) 1 "Integration between health care and research" aimed to generate recommendations for effective and efficient organization and management of research efforts.

**Figure 1.** JANE Work package distribution



The main objectives followed in this WP were:

- Mapping current challenges in the integration between health care and research in the perception of clinical researchers and physicians.
- Analyzing existing opportunities to conduct large clinical trials and to generate real-world evidence through networking.
- Improving the coordination of research by providing effective and efficient mechanisms by means of the new NoEs.





• Widening participation in research and improving the efficiency of research.

The aim of the first task of WP12 "Assessing current challenges in research portfolios and integration between health care and research" was to describe the challenges of integrating cancer research evidence into health care. Despite the availability of scientific evidence to improve cancer care and the benefits associated with its use, its implementation faces significant challenges due to several factors that have not been comprehensively investigated. The full report on the search strategy elaborated for this specific task can be found in Annex 1. This strategy included the preparation of a systematic review protocol, which has been published online on the PROSPERO database website with the protocol number CRD42024520574 that can be found here.

The definition of effective mechanisms and review of legal and regulatory aspects that could be applied to clinical research networks between NoEs, Comprehensive Cancer Centres (CCCs) and European Reference Networks (ERNs); and the study of mechanisms for the promotion of partnerships that can promote increased participation in funding opportunities, was carried out through the second task of WP12 "Establishing clinical research networks (CRN)".

The purpose of this document is to present the findings of these activities. The synthesis of this information has been translated into a set of recommendations based on how NoEs could work to better integrate research and health care, both in scientific and management approaches.

#### 2.2 Intended audience

The intended audience of this document is individuals involved in the NoEs or working in the field of health networks, EU institutions, decision-makers and policymakers, and other stakeholders of these networks in the future.





#### 3 METHODOLOGY

This section will offer a concise summary of the methodology used to develop the recommendations presented later in this document. These recommendations stem from the various outcomes of the WP12 activities conducted throughout the project.

The first task 12.1 related to the identification of current challenges in the integration of health care and research as perceived by clinical researchers and health professionals. While task 12.2 was aimed at different points, including the outline of research networking platforms, clarifying their operation and legal and regulatory aspects to serve as inspirational models for NoEs; the exploration of funding mechanisms and opportunities for research collaboration, including aspects to promote the collaboration itself; and aspects for the evaluation results of the NoEs' research efforts. The task 12.3 "Proposing guidelines for effective and efficient organization and management of research efforts facilitated by NoEs" was related to the preparation of this deliverable.

This deliverable also builds on the results of the activities of Task 4.1 "Mapping and analysis of existing networks" of the sustainability work package (WP4), aimed to gather information on key aspects of European networks, organizations and networking projects to support the first steps towards the sustainability of the NoEs. The lessons learnt from this analysis, include aspects related to research efforts of the studied organizations, which were also used as input for the elaboration of the final recommendations included in this document.

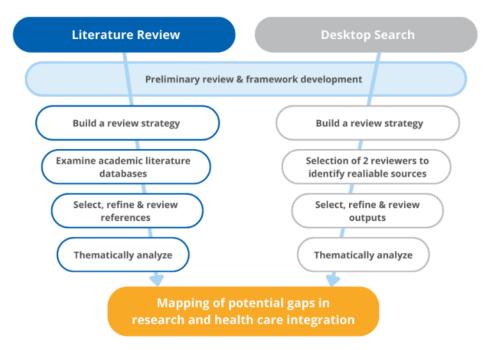
#### 3.1 Assessing challenges for integrating research results in health care

The first task of WP12, Task 12.1 "Assessing current challenges in research portfolios and integration between health care and research" as mentioned above, was addressed to describe the challenges of integrating cancer research evidence into health care. The task also included the definition of barriers and facilitators to integration.

To accomplish this task, the first step was to develop a search strategy that provided an agreed methodology for the analysis process. It was designed and agreed by all WP12 partners and includes two parallel phases: literature review and a desktop search. Basic aspects of the methodology used are explained below, but the full report on the methodology of this activity can be found in Annex I.



Figure 2. Methodology for the search strategy



The **literature review** is a search of scientific literature published in bibliographic databases, journal platforms, search engines and entities and official bodies. While the **desktop search** is a search of relevant grey literature that is produced by governments, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers (e.g. electronic journals).

The objective of these two phases was to map available evidence of potential gaps that need to be addressed to improve the integration between health care and research. The literature review was carried out by Biosistemak as the WP12 leader with the collaboration of one representative of the Institut Català d'Oncologia (ICO). While for the desktop search, two reviewers of each entity participating in WP12 were invited to suggest and include relevant resources related to the challenges and facilitators in the integration of health care and research.

#### Preliminary review and framework development

As shown in Figure 2, initially, a model based on the Innovative Care for Chronic Conditions (ICCC) of the World Health Organization (WHO, 2022) was developed based on previous work done by Abu-Odah and colleagues<sup>2</sup>. The ICCC Framework serves as a roadmap for policy development and the redesign of health care systems. Integration is a fundamental principle of the framework, emphasizing coordination

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<sup>&</sup>lt;sup>2</sup> Abu-Odah, H., Said, N. B., Nair, S. C., Allsop, M. J., Currow, D. C., Salah, M. S., Hamad, B. A., Elessi, K., Alkhatib, A., ElMokhallalati, Y., Bayuo, J., & AlKhaldi, M. (2022). Identifying barriers and facilitators of translating research evidence into clinical practice: A systematic review of reviews. *Health & social care in the community*, *30*(6), e3265–e3276. https://doi.org/10.1111/hsc.13898





55-64.

between different levels of the health care system, including the macro (policy environment), meso (community and health care organization), and micro (health care teams, patients, families, and community partners) levels. The framework highlights the importance of coordination and integration among these three levels, particularly in resource-limited contexts, to ensure effective and efficient chronic care<sup>3</sup>.

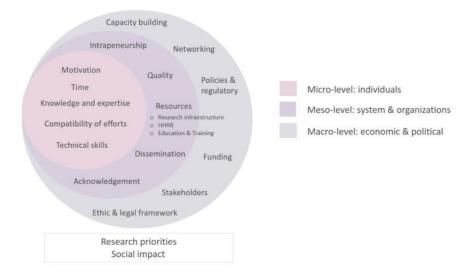
Following the ICCC Framework a preliminary review of the literature of the challenges and facilitators in the integration of research and health care was done by WP12 team, the main results of this research guided the definition of the "Framework of challenges and facilitators of the integration between research and health care". As shown in Figure 3, the framework included a total of three levels and one transversal field. Furthermore, it sets up a total of 18 areas distributed across the different levels of the health care system. The micro-level includes 5 areas related with individuals (motivation, time, knowledge and expertise, compatibility of efforts and technical skills); the meso-level includes a total of 5 areas which belongs to system and organizations aspects (Intrapreneurship, quality, resources, dissemination, acknowledgement); the macro-level includes 6 related with economic & political aspects (capacity building, networking, policies & regulatory, funding, stakeholders, ethic & legal framework); the transversal field includes 2 areas in regards with research priorities and social impact. The Annex I provides more information on this framework and the description of each of the areas included in the model.

https://doi.org/10.1016/j.healthpol.2011.10.006

<sup>&</sup>lt;sup>3</sup> Nuño, R., Coleman, K., Bengoa, R., & Sauto, R. (2012). Integrated care for chronic conditions: the contribution of ICCC Framework. Health policy (Amsterdam, *Netherlands),* 105(1),



**Figure 3.** Framework of challenges and facilitators of the integration between research and health care



The model set the theoretical framework, validated by WP12 partners and other JANE colleagues on an online workshop, set the model of reference for the Search Strategy developed in this task.

#### 3.1.1 Literature review

Conducting a literature review can help to understand and know more about the current state of a specific topic. It allows to identify gaps, inconsistencies and areas where further research is needed, thereby contributing to the development of a robust methodology based on previous findings<sup>4</sup>. It helps to avoid duplication of previous work, build upon existing knowledge, and ensure the reliability and validity of the methodology. Particularly, it could be useful in the context of European projects. This process could help to understand the diverse cultural, social and disciplinary context, enabling to identify common themes, disparities, and knowledge gaps across different regions, thus facilitating a more comprehensive and inclusive research design.

While there are different methods to conduct a literature review with various levels of rigor (from a systematic review to a narrative review), during the elaboration of the search strategy it was decided to opt for a systematic review. This resulted, in the preparation of a protocol entitled "Challenges in the Integration between Health Care and Research in the Cancer Field: A Systematic Review", which has been

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<sup>&</sup>lt;sup>4</sup> Arksey, H. and O'Malley, L. (2005) Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8 (1), 19–32. Available at: http://eprints.whiterose.ac.uk/1618/1/Scopingstudies.pdf





published online on the PROSPERO database with the protocol number CRD42024520574 and can be found <a href="https://example.com/here">here</a>5.

The basic aspects of this protocol are explained below, taking into account that initial aspects included in the search strategy in Annex I have been modified for this final version.

This systematic review was aimed to explore the available evidence to answer the following research questions:

- 1. What are the barriers of implementing cancer research evidence in health care?
- 2. What are the facilitators of implementing cancer research evidence in health care?

The identification of studies was conducted through electronic databases including Medline, CINAHL, Cochrane, EMBASE, Scopus, and Web of Science (WOS), the search syntax for each database can be found in Annex II. The review included all types of neoplasms, without restricting to any specific typology. The population included cancer patients across all areas and settings of oncology care.

There were no restrictions based on the publication date or study design, but the searches were limited to full-text publications in Spanish or English that addressed challenges in integration and reported barriers or facilitators. Narrative reviews or other types of articles such as letters to the editor, conference abstracts, or editorials were excluded. Grey literature was not included as it was part of the desktop search phase.

The records identified in the search were exported to the bibliographic manager RefWorks, then to Covidence to remove duplicates, and finally to Rayyan to proceed for the screening phase. Two reviewers independently screened all identified titles and abstracts based on inclusion criteria after duplicates were removed. Any disagreements were resolved through discussion and mutual agreement. After evaluating eligibility for the systematic review, the full text of selected studies was reviewed by two reviewers. Again, discrepancies were resolved through discussion and analysis, and if necessary, a third reviewer was involved to resolve any remaining disputes. The assessment of bias in the studies will use the Mixed Methods Appraisal Tool<sup>6</sup>, and the integrative methodology proposed by Whittemore

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts Dissemination Level – Public 18 Version 0.5

<sup>&</sup>lt;sup>5</sup> Sarah Berrocoso, Jesús González-Barboteo, Yhasmine Hamu Azcárate, Dolores Verdoy, Ane Fullaondo. Challenges in the Integration between Health Care and Research in the Cancer Field: A Systematic Review. PROSPERO 2024 CRD42024520574 Available

from: https://www.crd.york.ac.uk/prospero/display\_record.php?ID=CRD42024520574

<sup>&</sup>lt;sup>6</sup> Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., ... & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for information*, 34(4), 285-291.





and Knafl<sup>7</sup> will be used for data extraction and synthesis, as this phase of the review has not yet been carried out. As mentioned above, the systematic review was not yet complete at the time of preparation of this deliverable. For this reason, a number of preliminary descriptive analyses were carried out on the articles that passed the initial screening. Specifically, research hotspots of this field were analyzed based on co-word networks using VOSviewer software (version 1.6.20, developed by Van Eck and Waltman<sup>8</sup>). The bibliometric networks visualized by the VOSviewer are based on distance and each network consists of a large number of nodes that are mapped in a two-dimensional space on the basis of "visualization similarities", where each node represents a term. Node size indicates co-occurrence or occurrence, and the distance between two nodes represents their approximate association.

#### 3.1.2 Desktop search

The objective was to conduct a search in grey literature which includes a wide range of materials and research findings such as reports, theses, dissertations, conference proceedings, working papers, government documents and unpublished data. This data is produced and disseminated outside the traditional commercial or academic publishing channels.

Conducting a search in grey literature offers several benefits. Firstly, it helps access valuable research and information that may not be available in conventional published sources. This can offer real world-insights, policy evaluations or other type of practical experiences that complement the academic literature. Secondly, it often includes studies, data and reports that are not limited by the publication delays or access restrictions as peer-reviewed literature.

Based on the preliminary literature review and framework development (see above) areas related to strategies, barriers, and facilitators for the integration of research and health care practice were identified. To refine the search results in the desktop search, appropriate keywords, Boolean operators (AND, OR, NOT), and other search modifiers were utilized to refine the search results and obtain precise and targeted outcomes.

Considering that the members of WP12 were only from two countries, Slovenia and Spain, efforts were made to ensure the inclusion of documentation from a broader range of countries.

This task involved the following 7 organizations, which selected reviewers to conduct this activity.

ONKOLOSKI INSTITUT LJUBLJANA (OIL) – Slovenia

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<sup>&</sup>lt;sup>7</sup> Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of advanced nursing*, *52*(5), 546-553.

<sup>&</sup>lt;sup>8</sup> van Eck, N. J., & Waltman, L. (2010). Software survey: VOSviewer, a computer program for bibliometric mapping. *Scientometrics*, *84*(2), 523–538. https://doi.org/10.1007/s11192-009-0146-3





- Instituto Catalán de Oncología (ICO) Spain
- Fundación Instituto de Investigación Marqués de Valdecilla (IDIVAL) Spain
- Consorcio de Investigación Biomédica en Red (CIBER) Spain
- Hospital Sant Joan de Deu (HSJD) Spain
- Servicio Andaluz de Salud (SAS) Spain
- Instituto de Investigación en Sistemas de Salud BIOSISTEMAK Spain

The experts were required to identify different types of resources of the topic of interest. These resources could belong to the following typologies:

- Regulation and/or guidelines documents
- Strategic and consultation documents: plans, green papers or white papers
- Books that report empirical information
- Reports: institutional, internal, technical or statistical
- Project documents: deliverables, products, outcomes, from regional, national or European and international projects
- Guidance documents: guidelines on implementation and/or evaluation
- Good practices
- Other (specify)

The resources were identified through web search engines, websites, intranets, bulletins, publications of organizations or official bodies, repositories or other sources until December 2023. The reviewers analyzed the content and checked that it met the inclusion and exclusion criteria.

#### Inclusion criteria:

- Related to challenges in the integration of health care and research in the cancer field
- Linkable to at least one of the frameworks areas
- Evidence based
- Accessible (i.e., an ordinary reader/user can get hold of it/find it/locate it)
- Timeframe: last 10 years
- Languages: English, and languages of participant regions in the JANE project
- Geographic coverage: International

#### **Exclusion criteria:**

- Reported in academic publishing channels
- Confidential materials e.g., held under non-disclosure agreements





Then, the reviewers collected information for the retrieved resources and linked these documents to each of the areas found in the initial framework (Figure 3), that are:

1.	Motivation	10. Acknowledgement
2.	Time	11. Capacity building
3.	Knowledge and expertise	12. Networking
4.	Compatibility of efforts	13. Policies & Regulatory
5.	Technical skills	14. Funding
6.	Intrapreneurship	15. Stakeholders
7.	Quality	16. Ethic & Legal framework
8.	Resources (Infrastructure, HHRR, Education & Training)	17. Research priorities
9.	Dissemination	18. Social Impact

The description of each of the areas is included in Annex I. All extracted data were transferred to a common template, in which key aspects to describe the document were included. All the factsheets for each of the resources can be found in Annex III.

## 3.2 Establishing clinical networks

Task 12.2 "Establishing clinical research networks (CRN)" was addressed to define effective mechanisms for establishing clinical research networks to enable collaborative research. For this purpose clinical research platforms, funding programs and opportunities, and tools for evaluating NoEs were studied.

Firstly, collaborative research platforms were selected to clarify how they operate, and aspects related to their legal and regulatory functioning to serve as inspirational models for NoEs. The following entities were selected for this analysis:

- Clinical Research Units and Clinical Trials Platform (SCReN)
- European Cooperation in Science and Technology (COST Actions)
- Centre for Biomedical Research in Cancer Network (CIBERONC)
- Research Network on Chronicity, Primary Care and Prevention and Health Promotion (RICAPPS)
- European Rare Disease Research Coordination and Support Action consortium (ERICA)





- European Research Infrastructure Consortium (ERIC)
- <u>European Palliative Care Research Centre (PRC)</u>

This analysis also considered findings from the Task 4.1 "Mapping and analysis of existing networks" of the sustainability work package (WP4), which analyzed aspects related to research efforts of the following organizations: EURACAN, ESMO, EORTC, OECI, GENTURIS, UNCAN.eu, PCE, EAPC, PANCARE, EU-CAYAS-NET, TRANSLACORE, ESTRO, CCI Europe, PAEDCAN and SIOPE.

Secondly, funding mechanisms and opportunities for research collaboration were explored, where initiatives as the Cancer Mirror Groups, Horizon Europe and EU4Health programs, and other calls (e.g CanSERVs call) where included for analysis.

Finally, mechanisms to foster collaborative research and to evaluate of NoEs' results, and the lessons learned from the organizations studied were considered to develop the final set of recommendations.





#### 4 STATE OF PLAY

#### 4.1 Challenges for integrating research results in health care

This section provides a descriptive analysis of the results of the search strategy used in WP12, which includes the available evidence on gaps that need to be addressed to improve integration between health care and research and could serve as a basis for developing recommendations to be applied in NoEs.

The entire search strategy was based on the framework developed by the WP12 team, following an adaptation of the WHO Innovative chronic conditions model, after a preliminary literature review. While the desktop search for grey literature results was based on this framework where participants identified the emergence of these areas to facilitate the work and corroborate the existence of these areas for integration. The systematic review of electronic databases was open to the identification of new barriers and facilitators to this integration, and only the previous information from the framework was taken into account to elaborate the search protocol in the databases.

#### **Desktop search**

In the desktop search made in 2023, a total of 64 resources were identified. The distribution of the resources to the 18 framework areas are described below.

**Table 1.** Descriptive analysis of the areas of the framework identified in the desktop search

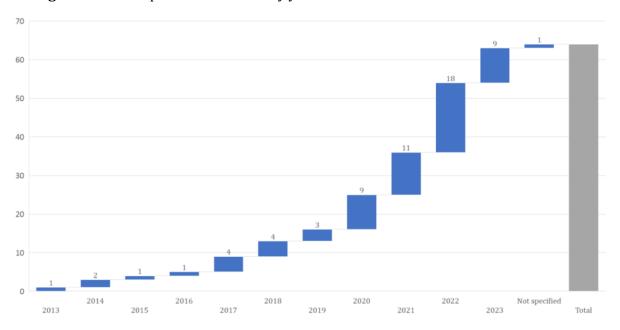
	Areas of the framework	N = 64	%
1	Motivation	8	5.1
2	Time	7	4.5
3	Knowledge and expertise	32	20.5
4	Compatibility of efforts	9	5.8
5	Technical skills	11	7
6	Intrapreneurship	6	3.8
7	Quality	11	7
8	Resources (Infrastructure, HHRR, Education & Training)	39	25
9	Dissemination	18	11.5
10	Acknowledgement	7	4.5
11	Capacity Building	9	5.8
12	Networking	23	14.7
13	Policies & Regulatory	23	14.7
14	Funding	29	18.6
15	Stakeholders	18	11.5
16	Ethic & Legal framework	11	7
17	Research priorities	9	5.8
18	Social impact	14	9



The most reported framework areas were knowledge and expertise (26.2%), resources (24.3%), policies and regulatory (17.9%), funding (17.9%) and networking (15.7%).

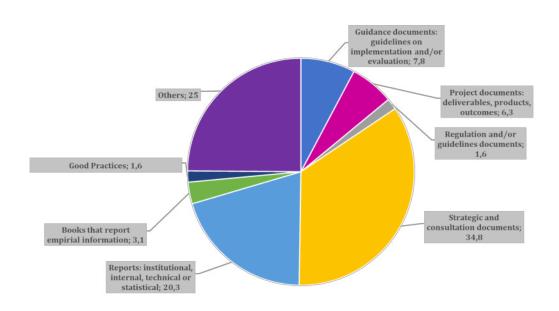
The graph below shows the year of publication of the resources mapped in the desktop search, which shows an increase in publications related to the topic of search analysis in recent years.

**Figure 4.** Desktop search resources by year



Most of the resources included in the desktop search were strategic and consultation documents (34.8%), or technical, statistical or internal reports (20.3%), such as, national or regional plans.

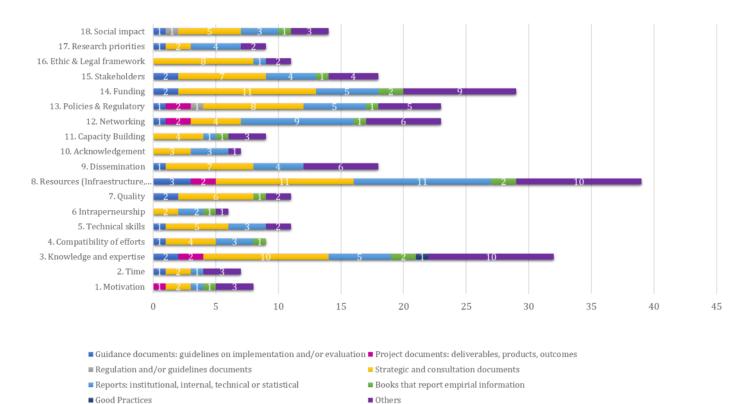
**Figure 5.** Desktop search type of resources (% over total resources)





The graph below shows the type of resources where each of the areas have been reported.

**Figure 6.** Desktop search resources by area and typology



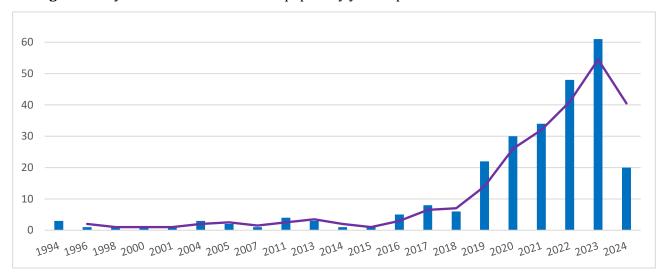
#### Literature review

A systematic search was performed to identify relevant articles published in databases without any time restriction. A total of 1388 scientific articles were identified from the selected databases. After the deletion of the duplicated sources, 680 studies were entered to the screening according to the inclusion and exclusion criteria. The systematic review is still under development and its results will be published in a scientific article. The current status of this review is available on the systematic review protocol website.

In the following, some partial results will be presented, relating to the 256 scientific articles that have passed through the first stage of the screening process to the next stage.



**Figure 7.** Systematic review scientific papers by year of publication



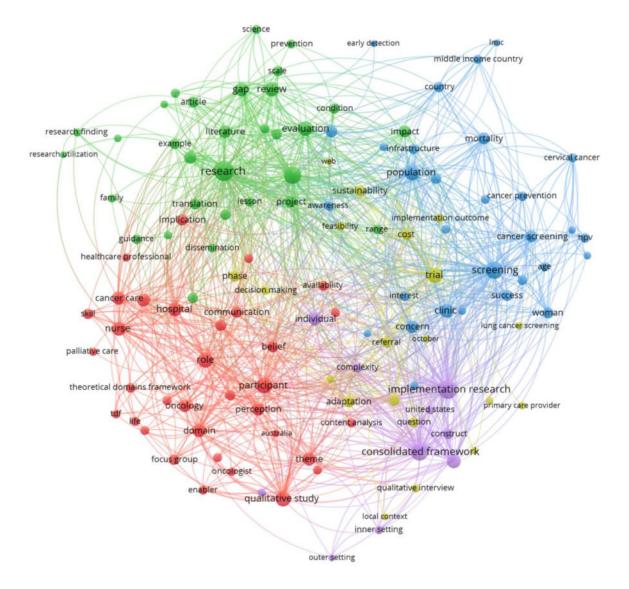
The number of articles published over the last three decades fluctuates to some extent, but the number of articles shows an increasing trend since 2016, with peaks particularly in 2022-2023, which may be related to research hotspots or an increasing interest in that topic.

A network visualization approach was employed to analyze the content of the 256 article titles and abstracts. The software offers three distinct map views: (1) a network visualization, which displays the results of identified topic clusters by similarity (2) and by date, and (3) a density visualization, which highlights the number of articles related to each topic.

The network visualization (Fig. 8, 9 and 10) revealed five distinct clusters of topics: 1) Cluster 1 (34 items) includes terms like *qualitative study, cancer care*, and *clinical practice*, which appear most frequently; 2) Cluster 2 (31 items) features topics such as *implementation science*, *evaluation*, and *research* as key elements; 3) Cluster 3 (30 items) is centered around *human papillomavirus*, *population*, and *screening*; 4) Cluster 4 (20 items) focuses on *costs*, *primary care*, and *trials*; and 5) Cluster 5 (10 items) highlights *implementation research*, the *consolidated framework*, and *CFIR*.



Figure 8. Network visualization – topic clusters

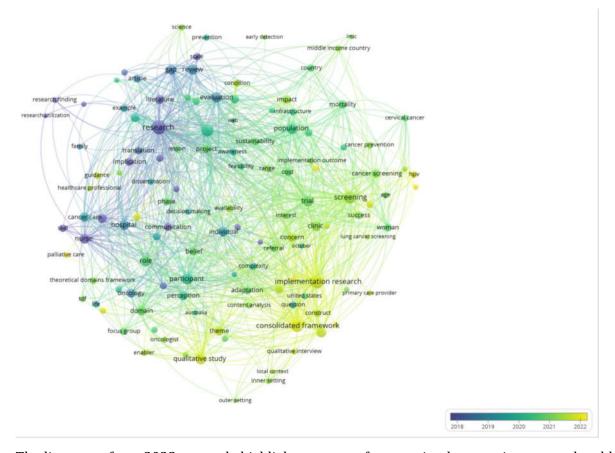


The analysis of the keywords co-occurrence network (Fig. 8), in which the keywords are labeled with colored circles and their size is correlated with the appearance of the words in the titles and abstracts of the publications (i.e., the greater the occurrence of the keyword, the greater the size of the text and circle), allows to perceive that the keywords with the biggest frequency are: (a) "research" (77); (b) "implementation research" (67); (c) "screening" (58); (d) "consolidated framework" (58); (e) "implementation science" (58); (f) "trial" (44); and (g) "evaluation" (39).

The overlay visualization in Figure 9, helps to track the chronological progression of topics, making it possible to identify emerging themes and trends, offering insights into the latest developments and growing research areas.



**Figure 9.** Network overlay visualization for the period 1994-2023



The literature from 2022 onwards highlights a strong focus on implementation research, addressing barriers and facilitators identified in various settings such as, cancer screening and palliative care integration, especially in low-resource settings. Key topics and trends include the promotion of health equity, human papilloma virus (HPV) vaccination strategies, and improving long-term follow-up for survivors, while precision medicine and genomic research have shown to play a prominent role in advancing personalized cancer care.

Specifically, there has been an increased focus on the trend of implementation research in this area. In this regard, the articles included in the systematic review from the last two years showcase the importance of contextual adaptation in implementation science for cancer-related interventions, highlighting the importance of frameworks, community involvement, and tailored approaches to meet the needs of diverse patient populations.

More concretely, various studies have highlighted significant barriers affecting access to cancer care, particularly for underserved populations. Issues such as financial constraints, competing health priorities, and lack of resources hinder effective intervention implementation. In contrast, facilitators





typically include strong leadership support<sup>9</sup>, stakeholder engagement<sup>10,11</sup>, adaptability of strategies and existing infrastructure for evidence-based interventions. In this sense, healthcare professionals' motivation and engagement are argued to be critical for implementing new interventions<sup>12</sup>. Their perspectives on barriers and facilitators can guide the adaptation and design of interventions, ensuring they meet patient needs and improve care delivery.

On other hand, the use of frameworks like the Consolidated Framework for Implementation Research (CFIR)<sup>13</sup> and RE-AIM<sup>14</sup> have shown to provide a structured approach to understanding and enhancing the implementation of evidence-based interventions in cancer care, such as cytoreductive surgery and electronic patient-reported outcome measures (ePROMs)<sup>15,16,17</sup>.

Finally, the density visualization in Figure 10 illustrates the concentration of terms across the dataset, highlighting areas with a higher frequency of occurrences. Some of the terms used more frequently

<sup>&</sup>lt;sup>9</sup> Hohl, S. D., Maxwell, A. E., Sharma, K. P., Sun, J., Vu, T. T., DeGroff, A., Escoffery, C., Schlueter, D., & Hannon, P. A. (2024). Implementing Mailed Colorectal Cancer Fecal Screening Tests in Real-World Primary Care Settings: Promising Implementation Practices and Opportunities for Improvement. *Prevention science: the official journal of the Society for Prevention Research*, *25*(Suppl 1), 124–135. https://doi.org/10.1007/s11121-023-01496-3

<sup>&</sup>lt;sup>10</sup> Friebel-Klingner, T. M., Alvarez, G. G., Lappen, H., Pace, L. E., Huang, K. Y., Fernández, M. E., Shelley, D., & Rositch, A. F. (2024). State of the Science of Scale-Up of Cancer Prevention and Early Detection Interventions in Low- and Middle-Income Countries: A Scoping Review. *JCO global oncology*, 10, e2300238. https://doi.org/10.1200/G0.23.00238

<sup>&</sup>lt;sup>11</sup> Wheeler, S. B., Lee, R. J., Young, A. L., Dodd, A., Ellis, C., Weiner, B. J., Ribisl, K. M., Adsul, P., Birken, S. A., Fernández, M. E., Hannon, P. A., Hébert, J. R., Ko, L. K., Seaman, A., Vu, T., Brandt, H. M., & Williams, R. S. (2023). The special sauce of the Cancer Prevention and Control Research Network: 20 years of lessons learned in developing the evidence base, building community capacity, and translating research into practice. *Cancer causes & control : CCC*, 34(Suppl 1), 217–239. https://doi.org/10.1007/s10552-023-01691-1

<sup>&</sup>lt;sup>12</sup> Petermann, V. M., Biddell, C. B., Planey, A. M., Spees, L. P., Rosenstein, D. L., Manning, M., Gellin, M., Padilla, N., Samuel-Ryals, C. A., Birken, S. A., Reeder-Hayes, K., Deal, A. M., Cabarrus, K., Bell, R. A., Strom, C., Young, T. H., King, S., Leutner, B., Vestal, D., & Wheeler, S. B. (2023). Assessing the pre-implementation context for financial navigation in rural and non-rural oncology clinics. *Frontiers in health services*, *3*, 1148887. https://doi.org/10.3389/frhs.2023.1148887

 $<sup>^{13}</sup>$  Shalowitz, D. I., Schroeder, M. C., & Birken, S. A. (2023). An implementation science approach to the systematic study of access to gynecologic cancer care.  $\it Gynecologic$  oncology, 172, 78–81. https://doi.org/10.1016/j.ygyno.2023.03.012

<sup>&</sup>lt;sup>14</sup> Ver Hoeve, E. S., Calhoun, E., Hernandez, M., High, E., Armin, J. S., Ali-Akbarian, L., Frithsen, M., Andrews, W., & Hamann, H. A. (2024). Evaluating implementation of a community-focused patient navigation intervention at an NCI-designated cancer center using RE-AIM. *BMC health services research*, *24*(1), 550. https://doi.org/10.1186/s12913-024-10919-y

<sup>&</sup>lt;sup>15</sup> Lai-Kwon, J., Rutherford, C., Jefford, M., Gore, C., & Best, S. (2024). Using Implementation Science Frameworks to Guide the Use of Electronic Patient-Reported Outcome Symptom Monitoring in Routine Cancer Care. *JCO oncology practice*, *20*(3), 335–349. https://doi.org/10.1200/OP.23.00462

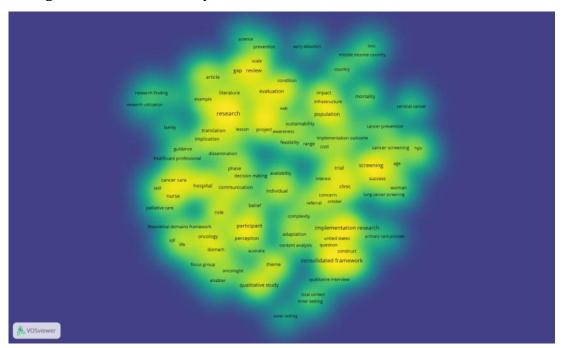
<sup>&</sup>lt;sup>16</sup> Skåre, T. S., Midtbust, M. H., Lund, J. Å., Kaasa, S., & Dreyer, A. (2023). Barriers and Facilitators When Implementing Electronic Patient-Reported Outcome Measures at a Municipal Cancer Care Unit: A Qualitative Study. *Cancer nursing*, 46(4), E268–E275. https://doi.org/10.1097/NCC.000000000001120

<sup>&</sup>lt;sup>17</sup> Telles, V. M., Rodriguez, S., Torres, M., Schneider, J., Haughton, J., Maldonado, M., & Arredondo, E. (2024). Barriers and facilitators to implementing a multilevel, multicomponent intervention promoting colorectal cancer screening in health centers: a qualitative study of key informant perspectives. *BMC health services research*, *24*(1), 404. https://doi.org/10.1186/s12913-024-10749-y



include research, evaluation, implementation research and frameworks to achieve evidence-based interventions. populations, cancer care and review of gaps.

Figure 10. Network density visualization







# 4.2 Advancing Collaborative Research: Mechanisms, Funding, and Evaluation Tools for NoEs

The first activity of Task 12.2 focused on learning from existing collaborative research networks to understand the types of activities they undertake, their funding mechanisms and how these insights could inspire the future structure of NoEs. The main objective was to explore how these networks operate, the types of activities they have developed and the potential benefits of their operation. This analysis, aimed at drawing a roadmap for the NoEs, involved the following networks: SCReN, Cost Actions, CIBERONC, RICAPPS, ERICA, ERIC, and PRC. Main conclusions of this analysis are presented in Table 2 and  $3^{18,19,20}$ .

<sup>&</sup>lt;sup>18</sup> COST [Website]. 2023. Available at: <a href="https://www.cost.eu/uploads/2022/04/20220419">https://www.cost.eu/uploads/2022/04/20220419</a> COST-Association - Statutes EN.pdf

<sup>&</sup>lt;sup>19</sup> European Commission: Directorate-General for Research and Innovation. (2015). ERIC practical guidelines: legal framework for a European Research Infrastructure Consortium. Publications Office. https://data.europa.eu/doi/10.2777/72348.

 $<sup>^{20}\,</sup>https://research-and-innovation.ec.europa.eu/strategy/strategy-2020-2024/our-digital-future/european-research-infrastructures/eric en$ 





**Table 2.** Summary of the selected European research collaboration networks

Network	Description	Type of activities	Source of funding
SCReN	CREN  A Spanish network dedicated to promoting and support of multicenter clinical trials.  Clinical research across multiple centers in Spain.		National and European public funding.
COST Actions	European program that funds research networks across various scientific fields.	Development of collaborative networks, scientific meetings, training programs.	EU funding through programs such as Horizon Europe (HE).
CIBERONC	A Spanish network for biomedical research in oncology, part of the larger CIBER initiative (Biomedical Research Networking Centers).	Translational research, clinical trials, and development of new therapies.	Funded by the Instituto de Salud Carlos III (ISCIII) and other national and European public funds.
ERIC	A legal framework that facilitates the establishment and operation of European research infrastructures of European interest.	Coordination of large research infrastructures, data management, training activities.	EU programs (e.g., H2020), Member State contributions, and contracts with academic or industrial institutions.
ERICA	A consortium integrating the research and innovation capacity of European Reference Networks (ERNs) focused on rare diseases.	Clinical research, development of therapies, improvement of clinical trial quality.	Funded by the EU's Horizon 2022 research and innovation program.
PRC	A center dedicated to research and improvement of palliative care across Europe.	Clinical research, training, development of best practice guidelines.	EU funding and other national and international sources.





**Table 3.** Operational functioning and possible advantages of the selected networks

Network	Operational functioning	Advantages
SCReN	Centralized coordination of trials, logistical and administrative support, data management assistance.	Facilitates the execution of multicenter clinical trials within Spain.
COST Actions	Managed by a steering committee and national subcommittees, organizes meetings and seminars to foster scientific collaboration.	Promotes scientific diversity and facilitates international collaboration, especially for researchers in countries with developing scientific capacities.
CIBERONC	Coordination of collaborative projects, support for clinical trial management, and knowledge transfer between institutions.	Enhances translational research in oncology, connecting research centers and hospitals across Spain.
ERIC	Organizational structure includes members (states or institutions), with a director and an assembly managing the operation and coordination of the infrastructure.	Provides a flexible legal structure allowing multinational collaboration, opportunities to participate in funding competitive calls, with tax benefits and VAT exemptions.
ERICA	Digital platform for collaborative research, centralized coordination, promotion of inter-ERN projects.	Integrates research and innovation across all ERNs, improving the quality and impact of clinical trials on rare diseases.
PRC	Collaboration among palliative care institutions, development of training programs, coordination of clinical research projects.	Improves the quality of palliative care in Europe through research and the development of guidelines and best practices.

Among these organizations, the ERIC system should be highlighted as it could currently serve as a model for inspiration or alignment with the European Commission's strategies regarding the operation of research infrastructures<sup>21</sup>. Previous publications have already argued that specific aspects of the ERIC

<sup>&</sup>lt;sup>21</sup> Moskovko, M. (2020). Intensified role of the European Union? European Research Infrastructure Consortium as a legal framework for contemporary multinational research collaboration. In Big science and research infrastructures in Europe (pp. 128-156). Edward Elgar Publishing.





model can be adapted for the use withing the ERNs<sup>22</sup>. However, the functions of ERNs extend far beyond merely providing resources and services for research. Therefore, flexibility and openness to innovation are crucial, particularly given that there are no established precedents for ERNs within the European Union. This publication highlights that all member states must collaboratively develop a common solution regarding the legal status of these networks, which adds another layer of complexity to their implementation and operation. This is for sure an aspect that could also be transferred to the NoEs.

#### Additional findings from WP4

Complementing the previous analysis, the main conclusions on aspects related to the research efforts of the organizations included in Task 4.1 of WP4, the following results may be highlighted.

Three figures have shown to reinforce the capability in the research infrastructure, including the existence of a **Scientific Advisory Board**, the existence of a **research strategy plan** and count with **applied research working groups**.

**Dissemination efforts** were found to be very important for all the organizations, networks and cancer projects evaluated. Some of the organizations, such as ESMO and EORTC, had the highest number of scientific publications, demonstrating the long track record of these organizations in the European cancer ecosystem. On the other hand, most of the organizations analyzed have published other types of resources, such as white papers, guidelines, recommendations, development of European standards and clinical criteria, infographics, public policy publications or other valuable literature for the field. In addition, all these organizations have shown that they participate in or coordinate different types of scientific events that facilitate knowledge transfer and make visible all the work and research efforts of such networks.

Moreover, 73.37% of the mapped organizations have participated in **European funded projects**, both as beneficiaries and in some cases also as coordinators. These dimensions were not applicable for three organizations as they are European funded projects (UNCAN.eu, EU-CAYAS-NET and TRANSLACORE). It must also be noted that participation in networks have shown to favor the generation of research opportunities thanks to the exchange of knowledge, and the ease of access to competitive funding.

<sup>&</sup>lt;sup>22</sup> Tumiene, B., Graessner, H., Mathijssen, I. M., Pereira, A. M., Schaefer, F., Scarpa, M., Blay, J. Y., Dollfus, H., & Hoogerbrugge, N. (2021). European Reference Networks: challenges and opportunities. *Journal of community genetics*, *12*(2), 217–229. <a href="https://doi.org/10.1007/s12687-021-00521-8">https://doi.org/10.1007/s12687-021-00521-8</a>





The mapping has shown how **some organizations provide its members with established structures for collaborative research**, such as infrastructure for data sharing (e.g. EAPC). Other organizations, like ESMO, include a Clinical Research Observatory with potentially useful functions such as providing views and recommendations to rationalize and streamline the bureaucracy associated with clinical research and boosting favorable environment for innovative and high-quality basic, translational, and clinical cancer research. Also, with **other types of resources** such as reference groups or task forces that could act as a focal point for discussion and exchange of knowledge, support the development and learning of early career researchers; or also by supporting the dissemination about competitive funding calls or direct grants for research and education for its members.

#### Funding opportunities and mechanisms

In relation to the funding opportunities at European level, an Europe-wide network was identified, the <u>Joint Action NFP4Health</u>, that aims to enhance the capacity of national focal points (NFPs) across EU member states, helping them design sustainable actions that align with the health objectives outlined for 2021-2027. Funded through the third EU health programme (2014-2020), the initiative promotes collaboration between NFPs by creating a sustainable and innovative network. This network supports the implementation of the EU4Health Programme by providing tools, resources, and information that help stakeholders, including applicants and beneficiaries, navigate health-related strategies, build synergies, and achieve their health goals.

In collaboration with the Horizon Health National Contact Point (NCP) network, HNN3.0, a fact sheet<sup>23</sup> was developed in January 2024 to provide health stakeholders with a side-by-side comparison of some of the key features and opportunities for health funding under the Horizon Europe Health Cluster (2021-2027), the EU4Health programme and Mission Cancer. Below are the opportunities included in this factsheet pertaining to the analysis of these organizations.

**Figure 11.** Health funding in EU4Health and Horizon Europe, a fact sheet by HNN 3.0 and NFP4Health

<sup>&</sup>lt;sup>23</sup> Available at: <a href="https://www.nfp4health.eu/2024/01/11/hnn-3-0-factsheet-health-funding-in-eu4health-and-horizon-europe/">https://www.nfp4health.eu/2024/01/11/hnn-3-0-factsheet-health-funding-in-eu4health-and-horizon-europe/</a>





	HNN 3.0		NFP4Health
	Horizon Europe Cluster Health	Mission Cancer	EU4Health
Focus	research and innovation		implementation and scale-up
Areas of action	Health throughout the life course     Environmental and social health determinants     Non-communicable and rare diseases     Infectious diseases including poverty-related and neglected diseases     Tools, technologies and digital solutions for health and care including personalised medicine     Health care systems	Addressing the entire cancer disease pathway:  Prevention Early detection Diagnosis and treatment Quality of life of cancer patients and survivors	Crisis preparedness Health promotion & disease prevention Health systems & healthcare workforce Digital transformation Cross-cutting focus on cancer

	HNN 3.0		NFP4Health	
	Horizon Europe Cluster Health	Mission Cancer	EU4Health	
Type of actions	Open competition:  Research & Innovation actions (RIA) Innovation actions (IA) Coordination & support actions (CSA) Pre-Commercial Procurement (PCP) Public Procurement of Innovative Solutions (PPI) Targeted calls for funding authorities (funding agencies, Member States' authorities): Programme co-fund actions (CoFund)		Direct Grants:  to Member States' authorities (nomination needed), including Joint Actions  to international organizations  to other entities (e.g., European Reference Networks and EU Reference Laboratories)  Grants with open competition:  Action Grants  Operating Grants to NGOs  Tenders & Procurement	
Target group	Academia with emphasis on the research community, NGOs, associations, healthcare providers, SMEs & industry, public authorities and -institutions		Public authorities and -institutions, academia, NGOs, associations, healthcare providers, private sector entities (to a smaller degree)	
Eligible countries	EU Member States + Overseas Countries and Territories ( <u>OCTs</u> ) + associated countries to HE + low- to middle-income non-EU countries		EU Member States + OCTs + Iceland, Moldova, Norway, Ukraine (Eligible beneficiaries of Grants)  All of the above + Georgia (Eligible tenderers of Procurements)  Entities from other countries not listed here may participate as Associated Partners in an EU4Health action if appropriate but may not receive funding from the programme.	





	HNN 3.0		NFP4Health					
	Horizon Europe Cluster Health	Mission Cancer	EU4Health					
Call cycle	Bi-annual work programmes	Yearly Call for Proposals	<ul> <li>Annual work programmes</li> <li>Yearly Call for Proposals: Operating Grants</li> <li>One or more wave(s) of Calls for Proposals per year for other Grants (Direct Grants incl. Joint Actions; Action Grants)</li> <li>Frequent Calls for Tenders</li> </ul>					
Funding rate grants	70% - 100%, 30% depending on type of action and type of organization	70% - 100% depending on type of action and type of organization	60% - 80% depending on consortium composition (countries)					
Managed by		HaDEA						
Find a call	Horizon Europe on the F&T	EU4Health on the F&T Portal						
Find your national point of contact	<u>List of NCPs</u>	<u>List of NFPs</u>						
Find resources via the contact point networks	https://www.healthncp.n	https://www.nfp4health.eu/						

*Note*. Original source available at: <a href="https://www.nfp4health.eu/wp-content/uploads/2024/03/Fact-sheet HE EU4Health v4.pdf">https://www.nfp4health.eu/wp-content/uploads/2024/03/Fact-sheet HE EU4Health v4.pdf</a>

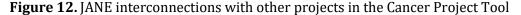
Along these lines and given that some of the MSs participating in JANE have this type of structure, such as Spain and Belgium, we wanted to study the work and activities of the cancer mirror groups more specifically. **Cancer Mirror Groups** play a crucial role in fostering collaboration and sharing knowledge among cancer research stakeholders. Their core activities revolve around dialogue and information exchange, achieved through consultations, emails, and regular meetings. These interactions help build bridges between different actors in the cancer research field, both at national and international levels. Additionally, the groups host informative events and workshops, targeting a wider audience to raise awareness about ongoing projects and initiatives. By mapping relevant activities and organizing policy events, they contribute to the coordination of research priorities and the alignment of cancer policy agendas across regions and countries.

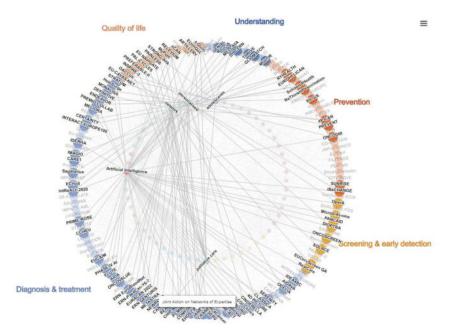
Furthermore, Cancer Mirror Groups actively engage in funding opportunities through national and regional calls, as well as by participating in international research consortia. This increases the likelihood of securing financial support for collaborative cancer research projects and encourages more institutions and researchers to get involved in European initiatives. Such engagement not only helps to strengthen local research efforts but also ensures alignment with broader European research objectives, making it easier to connect with relevant experts and resources.



The ECHOES project complements these efforts by establishing a European Network of Cancer Mission Hubs (NCMHs), which serves as a platform for collaboration across national, regional, and local levels. The NCMHs aim to enhance coordination among cancer research stakeholders in Europe, promoting synergies between local and European research initiatives. Through this network, researchers can easily access expertise from across the continent, benefit from shared resources, and increase their participation in European-funded projects. In turn, this fosters greater innovation in cancer research and enhances the capacity for large-scale, impactful studies, improving the chances of securing significant EU funding and accelerating advancements in cancer treatment and care.

Finally, one of the findings of the milestone "M10. Sustainability strategy of NoEs" of WP4, reported that that facilitating contacts with other projects in the field of cancer can improve the chances of collaboration in future joint projects. In this sense, the Knowledge Centre of Care recently launched an interactive online tool showing synergies and information on cancer-related projects funded by both EU4Health and Horizon Europe. **The EC Project Tool**<sup>24</sup> is a valuable asset for researchers, healthcare professionals, policy makers and other professionals seeking a structured and insightful overview of the EU's contributions to cancer research and public health initiatives. The tool is dynamic and responsive and will be updated regularly to incorporate new grant agreements. At this moment, the selection of projects is focused on cancer or its determinants, but the list provided could be not exhaustive.





Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 38 Version 0.5

<sup>&</sup>lt;sup>24</sup> Available at: <a href="https://knowledge4policy.ec.europa.eu/visualisation/cancer-projects-tool\_en">https://knowledge4policy.ec.europa.eu/visualisation/cancer-projects-tool\_en</a>





#### 5 RECOMMENDATIONS

This section lists the main recommendations derived from the WP12 activities and their rationale.

# 5.1 Key areas for action

The recommendations set out below for the NoEs aim to support and strengthen their capacity for effective and efficient organization and management of research efforts. It should be noted that a major focus of this analysis was to substantiate these recommendations based on the analysis of current gaps and facilitators in the integration of health care and research. Much evidence of this successful integration between health care and research can be found in the literature, however, there is further evidence that research does not translate into everyday practice. Therefore, it has been considered necessary to review the literature on the challenges and facilitators which may be encountered in practice prior to the implementation of the NoEs.

From the results of the desktop search the most frequently mentioned barriers to integrating research into healthcare practice were:

- Education and training deficits
- Resistance to change and professional barriers
- Loss of talent and disconnect between research and clinical practice.
- Barriers to implementation of patient-reported outcomes (PROMS): e.g. in palliative care.
- Lack of public commitment, investment and slow innovation.
- Complex interventions in complex systems: lack of coordination and adaptability of health systems hinders integration of research into care practice.
- Legal, ethical and regulatory challenges: Lack of standardization in data collection and limited interoperability between health information systems further hinder collaborative efforts.

The statements to be presented in Table 4 will include recommendations based on the various findings of the study activities in this transversal work package.





**Table 4.** Recommendations for effective and efficient organization and management of research efforts

Key Domains	Key Recommendations
Legal and financial	Formalize the legal status of NoEs to access competitive funding and ensure long-term stability
Fostering cross-border collaboration	Increase the sharing of knowledge and expertise across the EU to tackle the complexities of cancer.
Strengthening operational capacity	Define clear selection criteria and ensure early involvement of key stakeholders.
Adapting organizational models	Evaluate and adapt existing models to support research and improve clinical and policy communication.
Promoting implementation science	Simplify the bureaucracy of clinical trials and promote evidence-based practice with the support of advisory groups for NoEs.
Promoting interoperability	Aligning national strategies with European protocols in the context of the European Health Data Space.
Exploring federated data networks	Implementing networks that enable secure and efficient data exchange to accelerate research and improve health outcomes
Overcoming barriers	Addressing time, resource and regulatory constraints to facilitate research and dissemination of evidence-based practice





# 5.2 Added value of the recommendations

The presented recommendations are based on the work developed in JANE JA. In this sub-section these recommendations are compared to the existing supporting literature to support the initiatives put forward.

This work package has attempted to identify **barriers and facilitators** to the integration of research results into healthcare practice. The integration between these two fields could pose several challenges and consequences for professionals and patients. One of the most reported challenges in the literature, which has also been highlighted in the results of this WP, is the time constraints faced by health care professionals, as their demanding agendas may prevent them from staying updated on the latest research findings and implementing evidence-based practices<sup>25</sup>. Additionally, resource limitations, such as funding, the complex nature of research findings and the gap between research and clinical practice, can hinder the translation of the research into actionable strategies for patient care. The consequences of these challenges include potential variations in the quality of care provided, suboptimal patient outcomes, and a delay in implementing innovative and effective interventions. Patients may not receive the most up-to-date and evidence-based treatments, leading to disparities in health care quality. However, when successful integration between health care and research occurs, the consequences are positive, such as improved patient outcomes, enhanced health care quality, increased patient satisfaction, and the advancement of medical knowledge.

Based on the findings of this report, it is easy to see that although publications on the challenges of integration began to increase in 1994, the growth in the number of publications was not significant until 2016. The results of the visualizations of the interactions between terms also highlighted that, in the last decade, the topic of "implementation research" has started to become the focus of attention for the scientific community in this area. One of the articles included in the systematic review on breast cancer control programs proposes that global disparities in breast cancer outcomes are attributable to a sizable gap between evidence and practice in breast control and management<sup>26</sup>. That article also proposes dissemination and implementation science as a measure for optimizing the systematic uptake of evidence-based interventions and/or practices into real-world contexts. For these authors closing this gap will require deliberative and active dissemination and the implementation of evidence-based

<sup>&</sup>lt;sup>25</sup> Shayan, S. J., Kiwanuka, F., & Nakaye, Z. (2019). Barriers associated with evidence-based practice among nurses in low-and middle-income countries: A systematic review. Worldviews on Evidence-Based Nursing, 16(1), 12-20. https://doi.org/10.1111/wvn.12337

<sup>&</sup>lt;sup>26</sup> Rositch, A. F., Unger-Saldaña, K., DeBoer, R. J., Ng'ang'a, A., & Weiner, B. J. (2020). The role of dissemination and implementation science in global breast cancer control programs: Frameworks, methods, and examples. Cancer, 126 Suppl 10, 2394–2404. https://doi.org/10.1002/cncr.32877

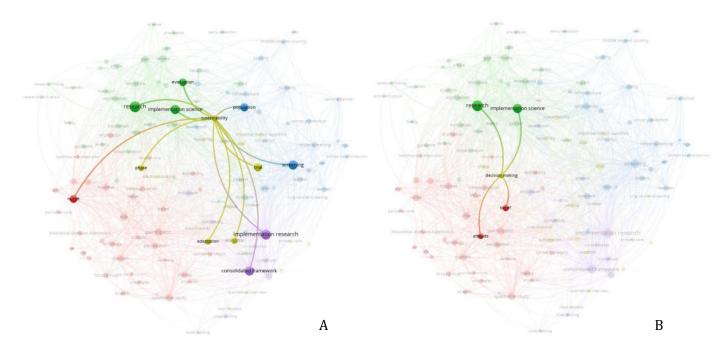




practices intro specific settings, by first translating research into contextually appropriate interventions, policies, and guidelines, and subsequently implementing these into practice.

Research in this area highlights that the key aspects of dissemination and implementation science, such as stakeholder engagement, application of theoretical frameworks, and rigorous ongoing evaluation, can be leveraged to optimize implementation from the individual to the system levels<sup>27</sup>. In this way, implementation science has come to be recognized for having the potential to accelerate and improve the translation of evidence-based programs, policies, products, and guidelines into real-world practice, enhancing their reach, speed, and effectiveness<sup>28</sup>. Moreover, implementation science hinges on understanding the multilevel context in which implementation occurs and engages stakeholders to ensure that strategies address the critical barriers; are feasible, acceptable, and appropriate; and are likely to be integrated, sustained, and scaled<sup>29</sup>.

Figure 13. Network visualization, topic links for sustainability and decision making



*Note.* The top two networks show the interrelationship of the terms (A) sustainability and (B) decision making. In the systematic review articles, sustainability is linked to terms such as research, evaluation,

<sup>&</sup>lt;sup>27</sup> Rubenstein LV, Pugh J. Strategies for promoting organizational and practice change by advancing implementation research. *I Gen Intern Med. 2006; 21*(suppl 2): S58-S64.

<sup>&</sup>lt;sup>28</sup> Glasgow, R. E., Ford, B. S., & Bradley, C. J. (2024). Implementation science for cancer control: One center's experience addressing context, adaptation, equity, and sustainment. *Translational behavioral medicine*, *14*(4), 215–224. https://doi.org/10.1093/tbm/ibad078

<sup>&</sup>lt;sup>29</sup> Neta, G. (2022). Implementation Science to Enhance the Value of Cancer Research in Latinos: A Perspective from the National Cancer Institute. In A. G. Ramirez (Eds.) et. al., Advancing the Science of Cancer in Latinos: Building Collaboration for Action. (pp. 143–148). Springer.





implementation science and research, screening and trials. This shows the perceived importance of the scientific community in these areas to ensure sustainable research. On the other hand, decision making is associated with beliefs, attitudes, research and implementation science as the main links, as presented later in this text.

This approach highlights the need for **stakeholder involvement** as a facilitator to overcome challenges in this integration process. Insufficient involvement of the public stakeholders and patients in research processes hinders the widespread adoption of new treatments and clinical trial results in routine practice<sup>30</sup>. Researchers and clinicians need to scale-up strategies including the development of stakeholder interrelationships, training and education<sup>31</sup> and, learn how to effectively communicate findings to stakeholders<sup>32,33,34</sup>. On this aspect, some of the resources found in the desktop search, pointed to the promotion of the maximum coordination between State and Regional planning and programming<sup>35</sup>, putting a particular focus on the point of view of companies and public-private collaboration, proposing measures to promote that research and innovations translates to the industrial tissue<sup>36</sup>.

As regards contact at **political levels**, currently, models exist to facilitate the translation of prevention research into evidence-based policymaking<sup>37</sup>. While there is growing recognition of the importance of grounding public policy in sound scientific evidence, numerous barriers still impede the efficient translation of prevention research into legislative measures. The pilot program developed by Fishbein et al., demonstrated that this kind of strategies can effectively mobilize prevention scientists, engage with legislative offices, connect policymakers with experts, and generate congressional requests for evidence on effective prevention strategies. In the same line of work, another of the barriers reported

<sup>30</sup> Luce Report on Lung Cancer: CHALLENGES IN LUNG CANCER CLINICAL TRIALS, Lung Cancer Europe

<sup>31</sup> Friebel-Klingner, T. M., Alvarez, G. G., Lappen, H., Pace, L. E., Huang, K. Y., Fernández, M. E., Shelley, D., & Rositch, A. F. (2024). State of the Science of Scale-Up of Cancer Prevention and Early Detection Interventions in Low- and Middle-Income Countries: Α Scoping Review. *ICO* global oncology, https://doi.org/10.1200/G0.23.00238

<sup>&</sup>lt;sup>32</sup> Improving the understanding, acceptance and use of oncology-relevant endpoints in HTA body / payer decisionmaking, Ryll B1, Mikhael J2, Gutierrez Ibarluzea I3, Morgan K4, Ocokoljic M6, Vassal G6, Van Poppel H7, Geissler J8, Gorgoni G9, Bolanos, N10, Milagre, T11 (2023)

<sup>&</sup>lt;sup>33</sup> The Heidelberg Manifesto on European Cancer Research, German Cancer Research Center (DKFZ) (2022)

<sup>&</sup>lt;sup>34</sup> World Declaration for Research on Cancer. World Cancer Research Day. Promoted by AECC, WHO, UICC, EACR, ESMO, NIH, ASCO, Cancer Research UK, AIRC and Dutch Cancer Society (2016)

<sup>&</sup>lt;sup>35</sup> Estrategia Española de Ciencia, Tecnología e Innovación 2021-2027, Ministry of science and innovation (2021)

<sup>&</sup>lt;sup>36</sup> Por una estrategia a largo plazo por la ciencia y la innovación en España, ASOCIACIÓN ESPAÑOLA DE INVESTIGACIÓN SOBRE EL CÁNCER (ASEICA) (2020)

<sup>&</sup>lt;sup>37</sup> Fishbein, D. H., Ridenour, T. A., Stahl, M., & Sussman, S. (2016). The full translational spectrum of prevention science: facilitating the transfer of knowledge to practices and policies that prevent behavioral health problems. Translational behavioral medicine, 6(1), 5-16. https://doi.org/10.1007/s13142-015-0376-2





in this deliverable has been the difficulties of access to training. Currently, there is evidence of successful training also in this area, to increase competence related to policy engagement and interactions with legislative staff<sup>38</sup>. The model proposed by Crowley et al., has been described as a powerful tool to effectively mobilize prevention scientists, foster connections with legislative offices, and generate specific requests for evidence to inform policymaking. Its structured approach enhances collaboration between researchers and policymakers, ensuring that scientific evidence is more effectively incorporated into legislative actions.





Note. Unknown source.

The **dissemination of research** has been recognized as a critical first step on the path toward knowledge and translation and practice change<sup>39,40</sup>. A commonly quoted estimate is that it takes an average of 17 years for 14% of published evidence to be widely incorporated into clinical practice<sup>41</sup>. By focusing on targeted communication strategies, researchers can convey their findings to key stakeholders in ways that align with the practical and policy needs of the cancer field. Particularly, the NoEs can benefit from its structure by developing targeted messages by engaging with systematic reviews, guideline development, and practice networks to ensure that scientific knowledge is translated into meaningful action within clinical and research settings.

The findings presented in this report have shown that other difficulties in achieving this translation are related to **lack of access to training opportunities**. Access to the latest research, especially in their

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public

44

Version 0.5

<sup>&</sup>lt;sup>38</sup> Crowley, M., Scott, J. T. B., & Fishbein, D. (2018). Translating Prevention Research for Evidence-Based Policymaking: Results from the Research-to-Policy Collaboration Pilot. *Prevention science: the official journal of the Society for Prevention Research*, 19(2), 260–270. https://doi.org/10.1007/s11121-017-0833-x

<sup>&</sup>lt;sup>39</sup> Edwards D. J. (2015). Dissemination of Research Results: On the Path to Practice Change. *The Canadian journal of hospital pharmacy, 68*(6), 465–469. https://doi.org/10.4212/cjhp.v68i6.1503

<sup>&</sup>lt;sup>40</sup> Estrategia de Salud Pública 2022, Spanish Ministry of Health (2022)

<sup>&</sup>lt;sup>41</sup> Westfall, J. M., Mold, J., & Fagnan, L. (2007). Practice-based research--"Blue Highways" on the NIH roadmap. *JAMA*, 297(4), 403–406. https://doi.org/10.1001/jama.297.4.403





own language, is often lacking for healthcare professionals. In addition, inadequate training in the application of research findings in clinical practice leaves staff underprepared to implement new evidence-based practices that could lead to opportunities for development, retention and career progression<sup>42,43</sup>. The literature supports that targeted policies aimed at attracting talent should strive to internalize and promote greater integration and multidisciplinarity in cancer research. This can be achieved by facilitating cross-training and transitions between fundamental, translational, and clinical research and among various disciplines, including nanotechnology, photonics, bioinformatics, and other scientific and technological fields, as well as epidemiology, economics, public policy, nursing, and healthcare professions, given the current challenges in achieving this level of integration<sup>44</sup>.

Among these proposals for improvement, there is also the recognition of merits related to research training, the encouragement and proper evaluation of scientific production, the facilitation of reconciliation with care practice (economic and time resources), continuous training in research methodology, assistance with attending specialized training and conferences, as well as the release of tasks and the creation of specific research positions<sup>45,46,47</sup>.

Moreover, the lack of research opportunities is often linked to the loss of talent, as many researchers leave for other countries with greater prospects in their field. In Spain and other parts of Europe, the oncology research system faces talent loss, bureaucratic delays, and funding cuts. These challenges have led to a growing disconnect between clinical needs and research outcomes, hindering the practical application of scientific breakthroughs in everyday cancer treatment, with clinical leaders recognizing the division of limited resources, restrictive employment contracts, and divergent

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<sup>&</sup>lt;sup>42</sup> Cancer: what are the barriers to research? Will West, Catherine Pickering, Kees Melief, John Maher, Jennifer Wheler and Klaas Zuideveld (2023)

<sup>&</sup>lt;sup>43</sup> GEICAM clinical practice guide for the diagnosis and treatment of metastatic breast cancer. GEICAM (Grupo Español de Investigación en Cáncer de Mama) (2015)

 <sup>44</sup> COMMITTED TO CANCER RESEARCH: First Report on Cancer Research and Innovation in Spain, Velasco (2018).
 45 Libro blanco de la investigación en enfermería en Euskadi, Juani Argomaniz, Sendoa Ballesteros, Encarnación Betolaza López de Gámiz, Mª Angeles Cidoncha Moreno, Lucía Elosegui Itxaso, Irrintzi Fernández Ahedo, Aintzane Orkaizaguirre, Javier Ortiz de Elguea Diaz, Janire Portuondo Jimenez, Fernando Ramos Peña, Vanesa Regúlez Campo, Sheila Sánchez Gómez, Jaione Santiago Garín, Ainhoa Ulibarri Ochoa, Gorka Vallejo de la Hoz, Sergio Yuste Muñoz, Jagoba Zarandona Calvo, Verónica Tíscar-González, Joan Blanco Blanco, Teresa Moreno Cascabas, Adolfo Romero Ruiz (2021).

<sup>&</sup>lt;sup>46</sup> Estrategia de investigación e innovación en Salud 2022-2025, Departamento de Salud, Gobierno Vasco (2022)

<sup>&</sup>lt;sup>47</sup> Libro blanco de la investigación en enfermería en Euskadi. Juani Argomaniz, Sendoa Ballesteros, Encarnación Betolaza López de Gámiz, Mª Angeles Cidoncha Moreno, Lucía Elosegui Itxaso, Irrintzi Fernández Ahedo, Aintzane Orkaizaguirre, Javier Ortiz de Elguea Diaz, Janire Portuondo Jimenez, Fernando Ramos Peña, Vanesa Regúlez Campo, Sheila Sánchez Gómez, Jaione Santiago Garín, Ainhoa Ulibarri Ochoa, Gorka Vallejo de la Hoz, Sergio Yuste Muñoz, Jagoba Zarandona Calvo, Verónica Tíscar-González, Joan Blanco Blanco, Teresa Moreno Cascabas, Adolfo Romero Ruiz (2021).





organizational priorities as additional barriers to collaboration and innovation<sup>48</sup>. Additionally, experts have pointed to funding shortages across both the private and public sectors, the influence of industry and academic priorities on research topics, regulatory barriers, and decentralized approaches that undermine collaboration and networking<sup>49</sup>.

These challenges not only hinder the practical application of research but also stifle **innovation**, hampering the integration of innovative findings into clinical practice. The lack of standardized data collection and limited interoperability between healthcare information systems further obstructs collaborative efforts. The solution provided by some of the recommendations found in the search is to ensure that existing screening programs make use of the most up-to-date, cutting-edge science results, and that these programs are an integral part of the overall cancer treatment strategy<sup>50</sup>. Coherent translational research, both for prevention and therapeutics, plays a crucial role in advancing multidisciplinary cancer research and driving innovation<sup>51</sup>. However, achieving this requires access to optimal research environments, in this sense, the cancer research continuum encompasses basic/preclinical research, early and late clinical research and, after the adoption of an innovation by the healthcare or health organizations, outcomes research. The translational research is often poorly connected across key components, leading to several critical gaps in the process, some authors point out that failures in innovative adoption in healthcare, results in major inequalities across and within countries and the unmet need for long-term follow-up in cancer patients.

The use of **design thinking approaches** has also been suggested to promote innovation in health care contexts<sup>52</sup>. Using design thinking methods has the potential to significantly improve care delivery models by developing services that better meet the needs of individuals and communities. To achieve this, health systems need to: (1) build capacity to identify and address both explicit and latent stakeholder needs; (2) engage a wider range of voices, especially from outside the health sector, and

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<sup>&</sup>lt;sup>48</sup> Day-Duro, E., Lubitsh, G., & Smith, G. (2020). Understanding and investing in healthcare innovation and collaboration. *Journal of health organization and management*, ahead-of-print(ahead-of-print), 10.1108/JHOM-07-2019-0206. https://doi.org/10.1108/JHOM-07-2019-0206

<sup>&</sup>lt;sup>49</sup> Cancer: what are the barriers to research? Will West, Catherine Pickering, Kees Melief, John Maher, Jennifer Wheler and Klaas Zuideveld (2023)

<sup>&</sup>lt;sup>50</sup> Cancer screening programmes need new foundations – Video of international conference held at MTA HQ, SAPEA - Science Advice for Policy by European Academies (2022)

 $<sup>^{51}</sup>$  Ringborg U. (2019). Translational cancer research - a coherent cancer research continuum. *Molecular oncology, 13*(3), 517–520. https://doi.org/10.1002/1878-0261.12450

 $<sup>^{52}</sup>$  Roberts, J. P., Fisher, T. R., Trowbridge, M. J., & Bent, C. (2016). A design thinking framework for healthcare management and innovation. *Healthcare* (*Amsterdam, Netherlands*), 4(1), 11–14. https://doi.org/10.1016/j.hjdsi.2015.12.002





constructively engage with different perspectives; and (3) rapidly test multiple hypotheses and solutions within communities most affected by persistent health problems.

Furthermore, the concept of implementation research is proposed again, as a bridge between research outcomes and practical healthcare applications. Its use could lead to updated clinical guidelines and these should recommend data collection for cancer registries to enable outcomes research on real-world data<sup>53</sup>. This quality-assured data collection is vital for assessing clinical utility and conducting health economic evaluations, ultimately ensuring cost-effectiveness and added value for patients and society<sup>54</sup>.

Finally, all these applications are affected by **bureaucratic and regulatory problems**. Clinical research, especially in Central and Eastern Europe, faces administrative burdens, regulatory hurdles, and slow approval processes, which prevent timely translation of research into practice. The need to define a management model that facilitates the scaling up, translation and implementation of priority R&D&I results in health care practice is also highlighted, as well as the possible funding of actions to support this translation<sup>55,56,57</sup>. Moreover, **strict data protection regulations**, such as the European Union's GDPR (Regulation EU 2016/679), create obstacles in medical data collection, transmission, and analysis, which slows this effective integration. The standardization process of data collection, that allows interoperability between cancer information systems, and adherence to internationally standardized protocols, merge as essential prerequisites for success in integrating innovation and improving cancer care <sup>58</sup>. The idea that research needs to be aligned with new technologies, such as big data and AI, so that it is possible to carry out large projects with a strong translational impact, with concrete opportunities to be quickly translated into new solutions for patients<sup>59</sup>.

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 $<sup>^{53}</sup>$  Bernards, René; Jaffee, Elizabeth; Joyce, Johanna A.; Lowe, Scott W.; Mardis, Elaine R.; Morrison, Sean J.; Polyak, Kornelia; Sears, Cynthia L.; Vousden, Karen H.; Zhang, Zemin . (2020). A roadmap for the next decade in cancer research. *Nature Cancer*, 1(1), 12–17. doi:10.1038/s43018-019-0015-9

<sup>&</sup>lt;sup>54</sup> Jönsson B and Sullivan R (2019) Mission-oriented translational cancer research – health economics. *Mol Oncol* 13, 636–647.

<sup>&</sup>lt;sup>55</sup> Estrategia de investigación e innovación en Salud 2022-2025, Departamento de Salud del Gobierno Vasco (2022).

<sup>&</sup>lt;sup>56</sup> Challenges in clinical research in Central and Eastern Europe – how can EORTC help? European Organisation For Research And Treatment of Cancer (EORTC) (2019)

<sup>&</sup>lt;sup>57</sup> Navigating Breast Cancer Research Funding Challenges: EORTC BCG and BIG Insights. European Organisation For Research And Treatment of Cancer (EORTC) & Breast International Group (2023)

<sup>&</sup>lt;sup>58</sup> Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population, R. Peiró Pérez, A. Molina Barceló, F. De Lorenzo, T. Spadea, S. Missinne, F. Florindi, N. Zengarini, K. Apostolidis, M. P Coleman, C. Allemani, M. Lawler (2017)

<sup>&</sup>lt;sup>59</sup> Fundazione Veronesi: Il nostro sostegno alla ricerca scietifica. Finanziamentei (2023)





#### 6 CONCLUSION

# 6.1 Next steps - Exploiting Networks of Expertise to Advance Research

This document is intended to provide recommendations for effective and efficient organization and management of research efforts, based on the analysis of current gaps and facilitators in the integration between health care and research and the definition of the necessary structures to carry out relevant clinical research. All these recommendations have been elaborated based on the results of the activities that have been carried out. However, this final section will reflect on how NoEs can be exploited to advance research in the early stages after its establishment.

Looking towards the future of collaborative mechanisms in European cancer research infrastructures, several approaches can be employed to leverage Networks of Expertise for advancing research and clinical practice. To date, mechanisms such as Coordination and Support Actions (CSAs), exemplified by initiatives like ERICA, have been established to enhance research opportunities within European Reference Networks (ERNs). Another critical framework is the European Research Infrastructure Consortium (ERIC), which could provide NoEs with formal legal status. This status is crucial as it opens up opportunities, including eligibility to participate in competitive funding calls that would otherwise be inaccessible.

In the short term, maintaining and expanding relationships with a broad range of stakeholders, including policymakers, healthcare professionals, and patients, is essential for promoting research within NoEs. These relationships play a vital role in supporting translational research, which aims to bridge the gap between laboratory findings and clinical applications. Addressing the barriers highlighted in this report, such as translating research into context-wise interventions, policies, and guidelines, is crucial for successful implementation into clinical practice.

In the mid-term, changes in organizational and research culture will be necessary. The establishment of NoEs offers new opportunities for collaboration, leading to the potential for new research proposals, stay visits, and other collaborative efforts. The success of similar frameworks, such as the European Cooperation in Science and Technology (COST) actions with their thematic networks, underscores the potential of NoEs in fostering research collaborations.

Implementing evidence-based practices should not be limited to clinical treatments or techniques but should also include adopting organizational models that support research services. NoEs can adapt these models to align with the national contexts of different Member States, facilitating a "network of networks" structure that enhances communication at both the clinical and political levels—an essential factor for driving change.





The science of implementation has demonstrated its importance in translational research. NoEs can capitalize on this by establishing streamlined protocols to reduce the bureaucracy surrounding clinical trials and providing cross-cutting support through advisory groups. For instance, in the ERICA project, EATRIS has played an instrumental role in building capacity by organizing workshops that help researchers adopt translational approaches and innovation strategies. EATRIS also provides databases that compile regulatory frameworks across participating countries, simplifying compliance and fostering research interoperability.

Aligned with these objectives, joint efforts in areas like research interoperability are crucial, particularly in the context of the European Health Data Space. Currently, with numerous initiatives focused on this topic, an ideal opportunity exists to start aligning national strategies with European protocols or to prepare for their deployment when the time comes. Learning from more advanced countries that can serve as reference models offers valuable insights, particularly when considering different starting points for implementation.

Moreover, the concept of Federated Data Networks is worth exploring. The Pediatric Health Data Space (PHEMS) project, for example, provides a unique model for sharing data interactively and securely across borders, facilitating faster research and improved health outcomes. This structure includes mechanisms for securing data through local agreements and compliance with local data protection regulations, making it a promising approach for broader application.

However, it is essential to address the barriers identified in this report, such as the limited time professionals have for research, the need for compatibility in efforts, gaps in knowledge and expertise, and the resources and infrastructures necessary for conducting research. Additionally, challenges related to networking, policies, regulations, and funding must be tackled. With the initial steps taken by NoEs in Europe, an ideal position exists to raise awareness of these issues, establish contacts with policymakers and potential stakeholders, and disseminate research results. This will help make evidence-based practices more accessible to the population and guide future research that aligns with cancer strategies and priorities.



# **ANNEXES**



# **ANNEX I JANE Search strategy**

EU4H-2021-JA-IBA







# WP12- TTF1 INTEGRATION BETWEEN HEALTH CARE AND RESEARCH

TASK 1 – SEARCH STRATEGY











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# **Overview**

JANE, the Joint Action on Networks of Expertise (NoEs) on Cancer, aims to establish seven Networks of Expertise in the cancer field by preparing everything necessary to launch them and critically evaluating existing models of current and future EU networking.

This action falls within the framework of the European Union's EU4Health Program, specifically the Joint Actions, which aim to foster cooperation, coordination, and knowledge-sharing among Member States in various areas of health policy and practice.

One of the flagship initiatives of Europe's Beating Cancer Plan for ensuring high standards in cancer care is the establishment, by 2025, of an EU network linking recognized National Comprehensive Cancer Centres (CCCs) in every Member State.

The ambition of JANE is to prepare and create new seven Networks of Expertise to cover crucial areas in cancer care, bringing together the best resources available in Europe in each specific field, in order to support National Networks and CCCs. The new NoEs will provide evidence in health care and clinical decision-making, research (clinical, translational and epidemiological), defining state-of-the-art and clinical practice guidelines, training professionals and patients, ensuring equitable access to available resources and having an impact on public policy. All this trying to maximize and shape the EU's investment and vision in terms of research infrastructure and platforms.

In particular, the Work Package (WP) 12 or transversal task force (TTF) 1 'Integration between health care and research' aims to generate recommendations for effective and efficient organization and management of research efforts.

To achieve this goal it will focus on the following specific objectives:

- Mapping current challenges in the integration between health care and research in the perception of clinical researchers and physicians.
- Analyzing existing opportunities to conduct large clinical trials and to generate realworld evidence through networking.
- Improving the coordination of research by providing effective and efficient mechanisms by means of the new NoEs.
- Widening participation in research and improve the efficiency of research.





This document contains the Search Strategy that will be used to study the challenges in the integration between health care and research. The integration between these two fields could pose several challenges and consequences for professionals and patients. One of the most reported challenges in the literature is the time constraints faced by health care professionals, as their demanding agendas may prevent them from staying updated on the latest research findings and implementing evidence-based practices (Shayan, Kiwanuka & Nakaye, 2019). Additionally, resource limitations, such as funding, the complex nature of research findings and the gap between research and clinical practice, can hinder the translation of the research into actionable strategies for patient care.

The consequences of these challenges include potential variations in the quality of care provided, suboptimal patient outcomes, and a delay in implementing innovative and effective interventions. Patients may not receive the most up-to-date and evidence-based treatments, leading to disparities in health care quality. However, when successful integration between health care and research occurs, the consequences are positive, such as improved patient outcomes, enhanced health care quality, increased patient satisfaction, and the advancement of medical knowledge.

Much evidence of this successful integration between health care and research can be found in the literature. It is considered necessary to examine in the literature the challenges and facilitators that can be encountered in practice before the implementation of JANE. This document provides the search methodology to conduct this literature review. The outcomes of the review will be the mapping of available evidence of gaps that need to be addressed to improve the integration between health care and research, and also the development of recommendations to be applied in future networks of expertise.





# List of abbreviations

CCCs	Comprehensive Cancer Centres
ССМ	Chronic Care Model
EU	European Union
HHRR	Human Resources
ICCC	Innovative Care for Chronic Conditions
MeSH	Medical Subject Headings
NoEs	Networks of Expertise
WHO	World Health Organization
WP	Work Package





# 1. Search Strategy

# 1.1 The Strategy

The Search Strategy provides an agreed methodology for the process of analysis. It has been designed and agreed by all WP12 partners and it includes two parallel phases: a literature review and a desktop search.

**Literature Review** Preliminary review & framework development **Build a review strategy Build a review strategy** Examine academic literature Selection of 2 reviewers to identify realiable sources databases Select, refine & review Select, refine & review references outputs Thematically analyze Thematically analyze Mapping of potential gaps in research and health care integration

Figure 1: Methodology for the mapping search

DELIVERABLE 12.1.

Recommendations for effective and efficient organization and management of research efforts

The *literature review* is a search of scientific literature published in bibliographic databases, journal platforms, search engines and entities and official bodies. The literature review will be related to the areas of analysis defined in the *Framework of challenges and facilitators of the integration between research and health care*.

The *desktop search* is a search of relevant grey literature that is produced by governments, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers (e.g. electronic journals). The focus of the desktop search will be also related with the areas of the *Framework of challenges and facilitators of the integration between research and health care.* 





The objective of these two phases is to map available evidence of potential gaps that need to be addressed to improve the integration between health care and research.

Kronikgune, as WP12 leader, will be the responsible of this task. The literature review phase, on the one hand, will be carried out by the Kronikgune team and cross-checked by the WP12 partners. On the other hand, for the desktop search, two experts in cancer of each entity participating in WP12 will be invited to suggest relevant resources related to the challenges and facilitators in the integration of health care and research. Additionally, Kronikgune will provide the templates to collect the information and will be responsible for gathering all the information provided by the partners in a timely manner.

Information from this search strategy will also be used for the development of the official project deliverable *D12.1 'Recommendations for effective and efficient organization and management of research efforts'* to be applied in future networks of expertise.





#### 2. Literature review

During the preparation of a research project or proposal, it is necessary to stay updated on the specific study field. This preliminary work allows for identifying gaps or needs in the area, enabling the development of impactful research within that context (Ding, 2001). Despite the increased accessibility to a multitude of electronic databases and research resources nowadays, the vast amount of available data and time constraints makes this task of staying updated a significant challenge. This challenge becomes even more apparent in emerging fields or research projects that explore broad areas within the literature.

In such cases, conducting a literature review can help to understand and know more about the current state of a specific topic. It allows to identify gaps, inconsistencies and areas where further research is needed, thereby contributing to the development of a robust methodology based in previous findings (Aksey & O'Malley, 2005). It helps to avoid duplication of previous work, build upon existing knowledge, and ensure the reliability and validity of the methodology.

Particularly, it could be really useful in the context of European projects. This process could help to understand the diverse cultural, social and disciplinary context, enabling to identify common themes, disparities, and knowledge gaps across different regions, thus facilitating a more comprehensive and inclusive research design.

While there are different methods to conduct a literature review with various levels of rigor (from a systematic review to a narrative review), an intermediate system has been chosen for this task that is described later in this document (Ato, Lopez & Benavente, 2013).

The next steps for the literature review will be followed:







Figure 2: Methodology for the literature review

# 2.1 Preliminary review & framework development

# 2.1.1 Background

Initially, a model based on the Innovative Care for Chronic Conditions (ICCC) of the World Health Organization (WHO, 2022) was developed based on previous work done by Abu-Odah and colleages (2022).

The World Health Organization (WHO) introduced the ICCC Framework in 2002 to address the increasing prevalence of chronic diseases. The ICCC Framework was built upon the Chronic Care Model (CCM), an evidence-based model developed in the 1990s by Wagner and colleagues. The ICCC Framework aimed to expand and adapt the CCM to make it applicable to a broader international context, addressing the limitations and gaps in the original model.





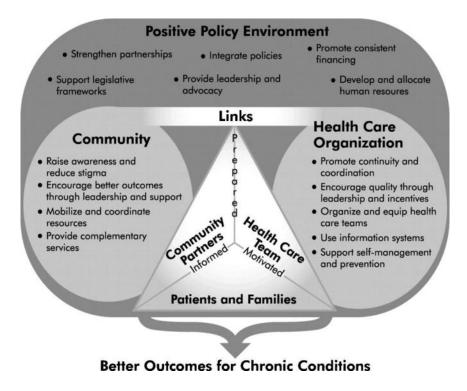


Figure 3: Innovative Care for Chronic Conditions (ICCC) Framework (WHO, 2002)

The ICCC Framework serves as a roadmap for policy development and the redesign of health care systems. It provides a set of "building blocks" that can be used to create or transform health care systems, aiming to harmonize initiatives worldwide to enhance chronic patient care. The framework incorporates a health policy perspective and facilitates comparative analysis and the identification of best practices. It has been used for policy development, health care redesign and analysis in different countries.

Integration is a fundamental principle of the framework, emphasizing coordination between different levels of the health care system, including the macro (policy environment), meso (community and health care organization), and micro (health care teams, patients, families, and community partners), as shown in **Errore. L'origine riferimento non è stata trovata.** The framework highlights the importance of coordination and integration among these three levels, particularly in resource-limited contexts, to ensure effective and efficient chronic care (Nuño, et al., 2012).







Figure 4: Adaptation of the levels of the WHO Innovative care for chronic conditions (ICCC) model

#### 2.1.2 Framework development

Following the ICCC Framework a preliminary review of the literature of the challenges and facilitators in the integration of research and health care was done by the Kronikgune team. The main results of this research guided the definition of the *Framework of challenges and facilitators of the integration between research and health care*.

The objective of this preliminary review was to map the scope and identify areas related to strategies, barriers, and facilitators for integrating research into health care practice. This type of analysis provides a comprehensive understanding of the literature, as the results indicate that this field of research is vast and encompasses various factors that can influence the integration process. This was one of the reasons that led us to follow the WHO model expressed in different levels, as other authors have done, as it facilitates their understanding and demonstrates the interaction that may be taking place between different levels of the context (Abu-Odah et al., 2022).



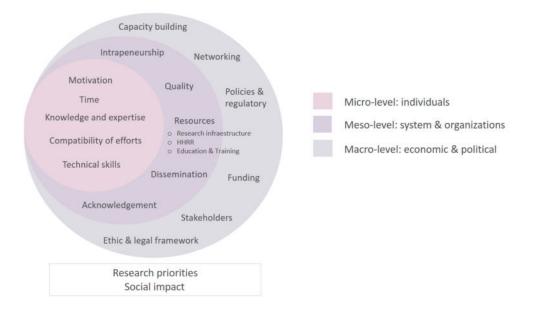


Figure 5: Framework of challenges and facilitators of the integration between research and health care

As shown in Figure 5, the framework includes a total of three levels and one transversal field. Furthermore, it sets ups a total of 18 areas distributed across the different levels of the health care system previously described.

The micro-level includes 5 areas related with individuals (motivation, time, knowledge and expertise, compatibility of efforts and technical skills); the meso-level includes a total of 5 areas which belongs to system & organizations aspects (intrapreneurship, quality, resources, dissemination, acknowledgement); the macro-level includes 6 related with economic & political aspects (capacity building, networking, policies & regulatory, funding, stakeholders, ethic & legal framework); the transversal field includes 2 areas in regards with research priorities and social impact. The ANNEX I includes more information about this framework and the description of each of the areas included in the model.

The model sets the theoretical framework of reference for the Search Strategy that is later presented in this document and was validated by the WP12 partners.

#### 2.2 Build a review strategy

Given the extensive volume of literature available on the integration between research and health care, the study will adopt a Scoping Meta-Review for a comprehensive synopsis of the field and identification of the current barriers and facilitators (Sarrami et al., 2015). This



typology of literature review serves as a comprehensive tool to assess and consolidate the findings of systematic reviews or meta-analyses, contributing to evidence-based decision-making and guiding further research efforts.

When conducting a scoping meta-review, study selection criteria can be developed iteratively (Arksey & O'Malley, 2005). An initial review strategy was developed at the beginning of the process based on the preliminary review, and it will be revised in the light of the search results. In this regard, the search equation or keywords used may be modified during the search.

The literature review will employ a strategy that outlines the sources and research questions, compiles documentary language for searching scientific databases (MeSH), establishes inclusion criteria, and the use of a reference manager for efficient collection and review of publications (RefWorks).

The search process will take place from June to August 2023 and will have an iterative approach, including language refinement and database searches until a satisfactory number of documents for review is obtained.

In a peer review exercise, the papers will be selected by examining all the titles and abstracts to ensure they meet the inclusion criteria and maintain consistency with the research question. The inclusion and exclusion criteria will be further defined.

# The research questions are:

- Which are the challenges faced by the integration of research and health care in the cancer field?
- Which are the facilitators in the integration of research and health care in the cancer field?
- What is the level of integration of research into clinical practice in cancer? How can it be promoted and facilitated?

Based on this literature review different search equations are conformed including the following terms:

- Medical subject headings: evidence based practice
- **Search terms (free terms):** cancer, barriers, facilitators.





# 2.3 Examine academic literature databases

The selected sources of search (scientific search databases) will be:

- CINAHL (<a href="https://www.ebsco.com/es/productos/bases-de-datos/cinahl-complete">https://www.ebsco.com/es/productos/bases-de-datos/cinahl-complete</a>)
- Cochrane (https://www.cochranelibrary.com/es/)
- EMBASE (OVID) (<a href="https://ovidsp.ovid.com/">https://ovidsp.ovid.com/</a>)
- PubMed/Medline (<a href="https://www.ncbi.nlm.nih.gov/pmc">https://www.ncbi.nlm.nih.gov/pmc</a>)
- Scopus (<a href="https://www.ncbi.nlm.nih.gov/pmc">https://www.ncbi.nlm.nih.gov/pmc</a>)
- Web of Science (WOS) (https://www.webofscience.com)

# 2.4 Select, refine & review references

#### Inclusion criteria:

- Related to challenges in the integration of health care and research, reporting barriers and/or facilitators
- Reviews (systematic, scoping, narrative and integrative reviews)
- Written in English or Spanish
- Papers published in the last 10 years

# **Exclusion criteria**

- Other type of articles such as letters for the editor, conference abstracts or editorials
- Publications where full-text versions could not be obtained

#### **Data extraction:**

All retrieved papers will be exported to Refworks Manager Software (<a href="https://refworks.proquest.com/public-">https://refworks.proquest.com/public-</a>

<u>share/ma1nhIX6ayTY6DvupbJaY47a6QM72LB631RNnILVyu6P</u>), then the duplicated articles will be deleted and the remaining will be screened for eligibility criteria by the Kronikgune reviewer's team.

The results will be collected in a data extraction sheet that includes the following information:

- Author, year of the study, number of articles included in the review
- Objective
- Type of design and analysis





 Main results (divided into barriers and facilitators) following the ICCC model as previously done (Abu-Odah et al., 2022)

# 2.5 Timeline - Literature review

Tasks	Start-End	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	Jun
Search Strategy (BS & ICO)	May 1 – Dec 31												
PROSPERO protocol	Dec 1 – Jan 31												
Data extraction (BS & ICO)	Jan 31 – Mar 31												
Data synthesis (BS & ICO)	Mar 31 – Apr 30												
Report Results (BS & ICO)	Apr 30 – Jun 30												
Review (ALL)	TBC												





# 3. Desktop search

The objective is to conduct a search in grey literature which includes a wide range of materials and research findings such as reports, thesis, dissertations, conference proceedings, working papers, government documents and unpublished data. This data is produced and disseminated outside the traditional commercial or academic publishing channels.

Conducting a search in grey literature offers several benefits. Firstly, it helps access valuable research and information that may not be available in conventional published sources. This can offer real world-insights, policy evaluations or other type of practical experiences that complement the academic literature. Secondly, it often includes studies, data and reports that are not limited by the publication delays or access restrictions as peer-reviewed literature.

The desktop research will follow these steps:

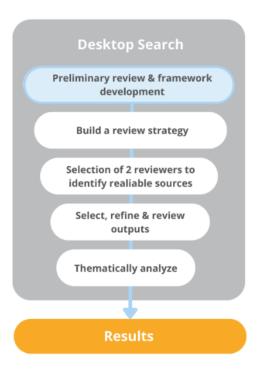


Figure 6: Methodology for the desktop search

#### 3.1 Build a Review Strategy

Based on the preliminary literature review and framework development (see section 2.1) areas related to strategies, barriers, and facilitators for the integration of research and health care practice were identified.





To refine the search results in the desktop search, appropriate keywords, Boolean operators (AND, OR, NOT), and other search modifiers will be utilized to refine the search results and obtain precise and targeted outcomes. Additionally, it is advisable to employ advanced search options offered by search engines or research databases to narrow down the search and filter results for this objective.

The members of WP12 belong to 2 countries – Slovenia and Spain -. Given that the total number of countries participating in JANE is 16, this represents only a minor part of them. Taking this fact into consideration, special attention will be paid to including content from all the countries participating in JANE. Furthermore, the inclusion of relevant data from other countries will be considered.

#### 3.2 Selection of reviewers and identification of reliable resources

Through this search, the identification and review of grey literature will be conducted, taking into account the theoretical framework developed in a preliminary phase.

The mapping exercise will gather records from all 16 countries represented within JANE. Data from other relevant countries for the objectives of the task may also be collected.

The following 7 organizations are taking part in this task:

- ONKOLOSKI INSTITUT LJUBLJANA (OIL) Slovenia
- Instituto Catalán de Oncología (ICO) Spain
- Fundación Instituto de Investigación Marqués de Valdecilla (IDIVAL) Spain
- Consorcio de Investigación Biomédica en Red (CIBER) Spain
- Hospital Sant Joan de Deu (HSJD) Spain
- Servicio Andaluz de Salud (SAS) Spain
- Instituto de Investigación en Servicios de Salud (KRONIKGUNE) Spain

Each organization will initially select two experts to carry on the desktop search. The collaboration of key agents in the field, who possess relevant expertise in the area and can contribute significantly to the purpose of this search, will be requested.

The next step is the identification of the most relevant and reliable resources that can be found in the following sources:

Web search engines





- Websites, intranets or bulletins
- Organizations and/or official bodies' publications
- Industry reports
- Repositories
- Other (specify)

The reviewers will analyze content from these sources and will need to verify that comply with the inclusion and exclusion criteria:

#### **Inclusion criteria:**

- Related to challenges in the integration of health care and research in the cancer field
- Linkable to at least one of the framework identified areas
- Evidence based
- Accessible (i.e., an ordinary reader/user can get hold of it/find it/locate it)
- Timeframe: last 10 years
- Languages: English, and languages of participant regions in the JANE project
- Geographic coverage: International

#### **Exclusion criteria:**

- Reported in academic publishing channels
- Confidential materials e.g., held under non-disclosure agreements

# Typology of the retrieved data

The reviewers will identify key information at regional, national or international level (related to challenges in the integration of health care and research in the cancer field), with the secondary objective of finding results that represent all participating member countries in JANE. Different types of data could be:

- Regulation and/or guidelines documents
- Strategic and consultation documents: plans, green papers or white papers
- Books that report empirical information
- Reports: institutional, internal, technical or statistical
- Project documents: deliverables, products, outcomes, from regional, national or European and international projects
- Guidance documents: guidelines on implementation and/or evaluation





- Good practices
- Other (specify)

# 3.4 Select, refine and review

After the first search step, the data will be screened. The reviewers will need to evaluate the outputs based on their relevance and alignment with the research objectives with the final objective of selecting a minimum of 5 resources.

In a first step they will classify and exclude studies based on titles and abstracts. During this process, the reviewers will collect specific information for each of the retrieved data and will also link these documents to each of the areas found in the initial framework.

The areas of the *Framework for assessing current challenges in integration between health care* and research are:

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1	П	П	1	N	lotivation	٠
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- 11. Time
- 12. Knowledge and expertise
- 13. Compatibility of efforts
- 14. Technical skills
- 15. Intrapreneurship
- 16. Quality
- 17. Resources (Infrastructure, HHRR, Education & Training)

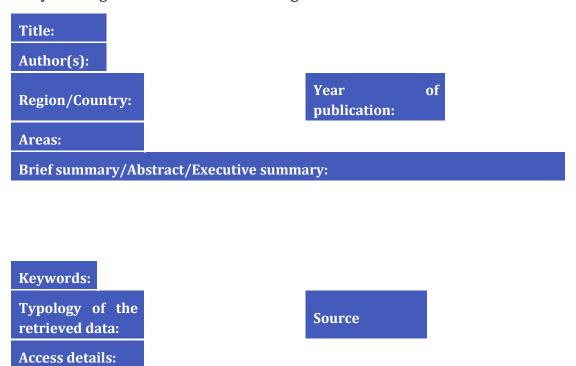
- 9. Dissemination
- 10. Acknowledgement
- 11. Capacity building
- 12. Networking
- 13. Policies & Regulatory
- 14. Funding
- 15. Stakeholders
- 16. Ethic & Legal framework

Transversal field: (17. Research priorities & 18. Social Impact)





The reviewers will include the search results in a structured manner using an Excel spreadsheet provided by Kronikgune team with the following information:



The experts will ensure that duplicated resources are not included. For this reason, an online document is used for the collection of information. Before including their identified and selected resources, experts should ensure that they have not been included by another expert.

The data to fill in the mapping template are listed below:

# Typology of the retrieved data

- o Regulation and/or guidelines documents
- Strategic and consultation documents: plans, green papers or white papers
- o Books that report empirical information
- Reports: institutional, internal, technical or statistical
- Project documents: deliverables, products, outcomes, from regional, national or
   European and international projects
- o Guidance documents: guidelines on implementation and/or evaluation
- Good practices
- Other (specify)
- **Areas**: Select the most suitable topic of analysis for the Framework: 1. Motivation, 2. Time, 3. Knowledge and expertise, 4. Compatibility of efforts, 5. Technical skills, 6.





Intrapreneurship, 7. Quality, 8. Resources (Infrastructure, HHRR, Education & Training), 9. Dissemination, 10. Acknowledgement, 11. Capacity Building, 12. Networking, 13. Policies & Regulatory, 14. Funding, 15. Stakeholders, 16. Ethic & Legal framework, 17. Research priorities and 18. Social impact.

- **Title**: Name of the document
- **Author(s)**: Main author(s)
- Year of publication: Year
- **Region/Country**: Region/Country from which the data is derived.
- Source:
  - Web search engines
  - Websites, intranets or bulletins
  - o Organizations and/or official bodies' publications
  - Industry reports
  - o Repositories
  - Other (specify)
- Brief summary/Abstract/Executive summary: Max 250 words
- **Keywords**: Free text
- Access details: URL





# Find below a completed example of the Desktop search mapping template:

Desktop search mapping template

Typology of the retrieved data: Report

Areas: 1, 6 & 7

Title: Implementation: The Missing Link Between Research and Practice

Author(s): Dean L. Fixsen & Karen A. Blase

Year of publication: 2009

Region/Country: Carolina, United States

Source: Organizations and/or official bodies' publications

Brief summary/Abstract/Executive summary: This document highlights the crucial role of implementation in bridging the gap between research findings and their practical application. It emphasizes that effective implementation requires a systematic and structured approach, focusing on factors such as leadership, staff training, and organizational culture. The authors discuss the importance of fidelity to the evidence-based practices and emphasize the need for ongoing monitoring and evaluation to ensure successful implementation. It also highlights the significance of collaboration between researchers and practitioners, as well as the importance of scaling up successful implementation efforts. Overall, the document emphasizes the need for a comprehensive implementation framework to enhance the translation of research into real-world practice.

Keywords: Research, Implementation, Innovation, Staff, Collaboration

Access details: https://files.eric.ed.gov/fulltext/ED507422.pdf

Contact reviewer ID: 1

The selected experts will be responsible for completing their Excel spreadsheet that will be available online in the following link: <a href="https://drive.google.com/file/d/1zFmonzc4M8iX00Y2pZaTrTXL47-">https://drive.google.com/file/d/1zFmonzc4M8iX00Y2pZaTrTXL47-</a>

nfTaJ/view?usp=drive link.





Kronikgune will upload Excel spreadsheets' information to the web-based software RefWorks (<a href="https://refworks.proquest.com/public-">https://refworks.proquest.com/public-</a>

<u>share/ma1nhIX6ayTY6DvupbJaY47a6QM72LB631RNnILVyu6P</u>) to use it as a repository and give access to the rest of the reviewers.

Kronikgune will lead the thematic analysis, summarize the gathered information, and report results.

# 3.5 Timeline - Desktop search

Tasks	s Start-End		Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb
Search Strategy (BS)	May 1 – June 30									
Identify (WP12 partners)	July 1 – Dec 31									
Select (WP12 partners)	Aug 15 – Dec15									
Review (WP12 partners)	Aug 15 – Dec 15									
Upload to Mendeley (BS)	Jan 1 — Jan 31									
Report Results (BS)	Jan 1 – Feb 29									





### 4. References

- Abu-Odah, H., Said, N. B., Nair, S. C., Allsop, M. J., Currow, D. C., Salah, M. S., Hamad, B. A., Elessi, K., Alkhatib, A., ElMokhallalati, Y., Bayuo, J., & AlKhaldi, M. (2022). Identifying barriers and facilitators of translating research evidence into clinical practice: A systematic review of reviews. *Health & social care in the community*, *30*(6), e3265–e3276. <a href="https://doi.org/10.1111/hsc.13898">https://doi.org/10.1111/hsc.13898</a>
- Arksey, H. and O'Malley, L. (2005) Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8 (1), 19–32. Available at: <a href="http://eprints.whiterose.ac.uk/1618/1/Scopingstudies.pdf">http://eprints.whiterose.ac.uk/1618/1/Scopingstudies.pdf</a>
- ATO, Manuel; LOPEZ, Juan J. y Benavente, Ana. Un sistema de clasificación de los diseños de investigación en psicología. Anal. Psicol. [online]. 2013, vol.29, n.3, pp.1038-1059. ISSN 1695-2294. https://dx.doi.org/10.6018/analesps.29.3.178511.
- Ding Y, Chowdhury GG, Foo S. Bibliometric cartography of information retrieval research by using co-word analysis. *Inf Process Manage*. 2001; 37 (6): 817 842
- Nuño, R., Coleman, K., Bengoa, R., & Sauto, R. (2012). Integrated care for chronic conditions: the contribution of the ICCC Framework. *Health policy (Amsterdam, Netherlands)*, 105(1), 55–64. https://doi.org/10.1016/j.healthpol.2011.10.006
- Sarrami-Foroushani P, Travaglia J, Debono D, Clay-Williams R, Braithwaite J. Scoping metareview: introducing a new methodology. Clin Transl Sci. 2015 Feb;8(1):77-81. doi: 10.1111/cts.12188. Epub 2014 Jul 15. PMID: 25041546; PMCID: PMC5350913.
- Sarrami-Foroushani, P., Travaglia, J., Debono, D., Clay-Williams, R., & Braithwaite, J. (2015). Scoping meta-review: introducing a new methodology. *Clinical and translational science*, 8(1), 77–81. <a href="https://doi.org/10.1111/cts.12188">https://doi.org/10.1111/cts.12188</a>
- Shayan, S. J., Kiwanuka, F., & Nakaye, Z. (2019). Barriers associated with evidence-based practice among nurses in low-and middle-income countries: A systematic review. *Worldviews on Evidence-Based Nursing*, 16(1), 12–20. <a href="https://doi.org/10.1111/wvn.12337">https://doi.org/10.1111/wvn.12337</a>
- World Health Organization. Noncommunicable Diseases and Mental Health Cluster. (2002). Innovative care for chronic conditions: building blocks for actions: global report. World Health Organization. <a href="https://apps.who.int/iris/handle/10665/42500">https://apps.who.int/iris/handle/10665/42500</a>





# ANNEX I – Framework for assessing current challenges in integration between health care and research

### MICRO-LEVEL

- **Motivation:** Interest in updating knowledge on emerging best practices. Conviction over the potential of translating research evidence into clinical practice.
- **Knowledge and expertise:** Ability of health care professionals to use health research findings and recommendations for clinical research practice. Professional's familiarity with evidence-based practice concepts.
- **Technical skills:** Sufficient critical appraisal skills of health care professionals (e.g. methodological procedures for research).
- **Time:** Time dedicated to staying updated, access to reputable research resources, multidisciplinary team collaborations, and the development of streamlined processes for evaluating and implementing new evidence.
- **Compatibility of efforts:** Actions and initiatives undertaken by health care professionals to align their clinical practices with the latest research evidence.

## **MESO-LEVEL**

- Resources (research infrastructure; HHRR; education & training): Time availability
  (that organizations provide to professionals to carry out these tasks), workforce
  adequately skilled to read and understand research processes, adequate facilities,
  materials and equipment to conduct research, such as, access to academic research
  databases (Scopus, Web of Science, PubMed...).
- **Quality:** Existence of guidelines that promote high quality clinical practices.
- **Dissemination:** Rich knowledge dissemination and access to evidence and research of health care professionals.
- **Intrapreneurship:** Facilitation and encouragement of employees to generate creative and innovative ideas within a company, by valuing their ideas and converting them into a profit model for the organization.
- **Acknowledgement:** Recognition by organizations serves as a catalyst for health care professionals to continue their efforts for conducting research. It provides validation,





support, networking opportunities and resources, fostering a culture of evidence-based medicine and ultimately improving patient care and organizational outcomes.

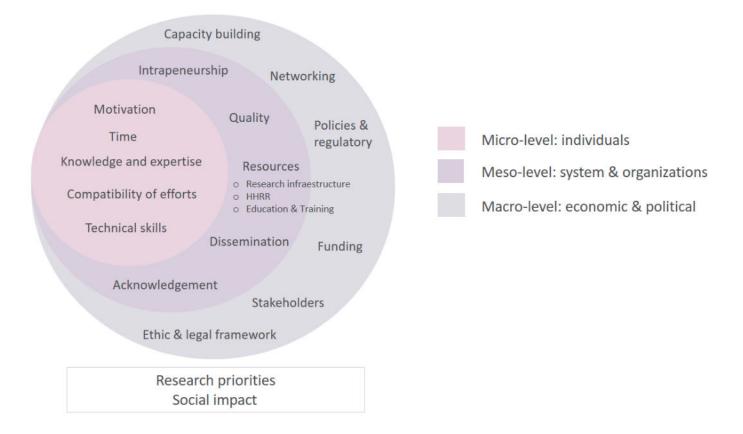
### **MACRO-LEVEL**

- **Capacity building:** Development and reinforcement of the skills, instincts, abilities, processes and resources that organizations and communities need to survive, adapt, and thrive in a fast-changing world (such as promoting training opportunities).
- Policies & Regulatory: Development of guidelines, rules, and frameworks established by governing bodies, regulatory agencies and health care organizations to administrate the process of incorporating research findings into routine patient care. It could include policy-makers trust in the potential of translating research into clinical practice (health policy development and systematic public investment in research programs) and regulatory processes such as approval for drugs, medical devices and therapies.
- **Funding:** Economical support given for an event, initiative, project or activity.
- **Stakeholders:** Person, group or organizations with a vested interest or stake in the decision-making and activities of an organization (evidence producers and the beneficiaries of research, such as the community).
- Networking: Robust collaborations and connections between policy-makers and research staff (health care professionals conducting research). Interactive models providing all the stakeholders and the beneficiaries with constant engagement and updated information.
- Ethic & legal framework: set of guidelines and regulations that govern the conduct of research and health care practices. It encompasses principles of ethics, such as informed consent, confidentiality, and protection of human rights, as well as legal requirements related to data privacy, intellectual property, and compliance with clinical trial regulation.





# ANNEX II – Framework for assessing current challenges in integration between health care and research (figure)







# ANNEX II Database search syntax

#### Medline via PubMed

("research utiliz\*"[Title/Abstract] OR "implementation science"[Title/Abstract] OR "implementation science"[MeSH]) ("barrier\*"[Title/Abstract] OR "facilitator"[Title/Abstract] OR "challenge\*"[Title/Abstract] OR "difficult\*"[Title/Abstract] "problem\*"[Title/Abstract]) "limitation\*"[Title/Abstract] OR OR AND ("Neoplasms"[MeSH "cancer\*"[Title/Abstract] Terms] OR "neoplas\*"[Title/Abstract] OR OR "oncolog\*"[Title/Abstract] "tumour\*"[Title/Abstract] "Carcinoma"[Title/Abstract] OR OR OR "tumor\*"[Title/Abstract] OR "malignan\*"[Title/Abstract] OR "Hematologic Neoplasms"[MeSH Terms] OR "Hematologic Neoplasms"[Title/Abstract] OR "hematologic malignanc\*"[Title/Abstract] OR "haematologic malignanc\*"[Title/Abstract] OR "haematological malignanc\*"[Title/Abstract] malignanc\*"[Title/Abstract] OR "Hematological cancer"[Title/Abstract] OR "Haematological cancer"[Title/Abstract])

Date	14/05/2024
Results	347
Refined results (document type)	181

### Web of Science

((TS=("research utiliz\*" OR "implementation science")) **AND** TS=(barriers OR facilitators OR challenges OR limitations OR difficulties OR problems)) **AND** TS=(neoplasms OR cancer OR carcinoma OR oncology OR tumour OR tumor OR malignant OR malignancy OR hematologic neoplasms OR hematologic malignancies OR hematological malignancy OR hematological cancer)

S4	#3 AND #2 AND #1
S3	TS=(neoplasms OR cancer OR carcinoma OR oncology OR tumour OR tumor OR malignant OR malignancy OR hematologic neoplasms OR hematologic malignancies OR hematological malignancy OR hematological cancer)
S2	TS=(barriers OR facilitators OR challenges OR limitations OR difficulties OR problems)
S1	TS=("research utiliz*" OR "implementation science")

Date	14/05/2024
Results	351
Refined results (document type)	335

#### **Embase**

("research utilization" OR "implementation science"):ti,ab,kw AND (barrier\* OR facilitator OR challenge OR limitation\* OR difficult\* OR problem\*):ti,ab,kw AND (neoplasms OR neoplas\* OR cancer\* OR carcinoma OR oncolog\* OR tumour\* OR tumor\* OR malignan\* OR "hematologic neoplasms" OR "hematologic malignanc\*" OR "hematologic malignanc\*" OR "hematological cancer"):ti,ab,kw

Date	21/05/2024
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Results	305
Refined results (document type)	189

#### **Cinahl Complete**

S4	(S1 AND S2 AND S3))
S3	neoplasms OR cancer OR carcinoma OR oncology OR tumour OR tumor OR malignant OR malignancy OR hematologic neoplasms OR hematologic malignancies OR hematological malignancy OR hematological cancer
S2	barriers OR facilitators OR challenges OR limitations OR difficulties OR problems
S1	research utilization OR implementation science

Date	21/05/2024
Results	140
Refined results (document type)	130

#### Cochrane

("research utilization" OR "implementation science"):ti,ab,kw AND (barrier\* OR facilitator OR challenge OR limitation\* OR difficult\* OR problem\*):ti,ab,kw AND (neoplasms OR neoplas\* OR cancer\* OR carcinoma OR oncolog\* OR tumour\* OR tumor\* OR malignan\* OR "hematologic neoplasms" OR "hematologic malignanc\*" OR "hematologic malignanc\*" OR "hematological cancer"):ti,ab,kw

Date	14/05/2024
Results	62
Refined results (document type)	62

### **Scopus**

( TITLE-ABS-KEY ( "research utiliz\*" OR "implementation science" ) AND TITLE-ABS-KEY ( barrier\* OR facilitator OR challenge OR limitation\* OR difficult\* OR problem\*) AND TITLE-ABS-KEY ( neoplasms OR neoplas\* OR cancer\* OR carcinoma OR oncolog\* OR tumour\* OR tumor\* OR malignan\* OR "hematologic neoplasms" OR "hematologic malignanc\*" OR "hematologic malignanc\*" OR "hematologic acancer" ) )

Date	14/05/2024
Results	527
Refined results (document type)	491



Access details:



# **ANNEX III JANE Desktop search resources found**

Title:	Cancer screening in	Cancer screening in the European Union (2017). Report on the implementation of the Council Recommendation on cancer screening (second report).						
Author(s):		IARC in collaboration with CPO Piemonte and University Hospital "Città della Salute e della Scienza" (Turin, Italy) and the Mass Screening Registry/Finnish Cancer Registry (Helsinki, Finland). Ponti A, Anttila A, Ronco G, Senore C, Basu P, Segnan N, et al.						
Region/Count	y:	Europe	Year of publication	2017	Areas:	2,3, 11, 12		
Brief summary	/Abstract/Executive	summary:						
demonstrate a f decision-making necessary to kn public health im	avourable balance of bog criteria are essential to ow its social and health	enefits and harms, be o improve quality, ma impact in advance. R	cost-effective, affordable a ximise benefits and minimi egular analysis and reporti	and acceptable. Consense harms. This doing of the perform	Ongoing monitori ocument suppor mance of cancer	alone isn't enough to recommend screening, evaluation, research, evidence synthets the idea that in order to implement a his screening programmes in EU Member Sting efforts to improve the quality and impose	esis and assessment of health intervention, it is tates is of considerable	
Keywords:	Evidence; screening; r	esearch; impact; colla	borative relationships; data	a; platform				
Typology of th	e retrieved data:	Guidance docui	· ·	on Source:		Organizations and/or official bodies' pub	lications	

https://health.ec.europa.eu/system/files/2017-05/2017 cancerscreening 2ndreportimplementation en 0.pdf





Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population Title:

Author(s):

IARC in collaboration with CPO Piemonte and University Hospital "Città della Salute e della Scienza" (Turin, Italy) and the Mass Screening Registry/Finnish Cancer Registry (Helsinki, Finland). Ponti A, Anttila A, Ronco G, Senore C, Basu P, Segnan N, et al.

**Region/Country:** Europe Year of publication: 2017 Areas: 2,3, 11, 12

### **Brief summary/Abstract/Executive summary:**

The EU Council's 2003 cancer screening programmes are based on scientific evidence of effectiveness, but effectiveness alone isn't enough to recommend screening. Programmes must demonstrate a favourable balance of benefits and harms, be cost-effective, affordable and acceptable. Ongoing monitoring, evaluation, research, evidence synthesis and assessment of decision-making criteria are essential to improve quality, maximise benefits and minimise harms. This document supports the idea that in order to implement a health intervention, it is necessary to know its social and health impact in advance. Regular analysis and reporting of the performance of cancer screening programmes in EU Member States is of considerable public health importance and should be continued. This document presents a series of steps to be considered for continuing efforts to improve the quality and impact of cancer screening programmes in EU Member States.

**Keywords:** Evidence; screening; research; impact; collaborative relationships; data; platform

Guidance documents: guidelines on Organizations and/or official bodies' publications Typology of the retrieved data: Source: implementation and/or evaluation

https://health.ec.europa.eu/system/files/2017-05/2017 cancerscreening 2ndreportimplementation en 0.pdf Access details:

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Council Recommendation of 9 December 2022 on strengthening prevention through early detection: A new EU approach on cancer screening replacing Council Title: Recommendation 2003/878/EC 2022/C 473/01 Author(s): The Council of the European Union Year of publication: **Region/Country:** Europe 2022 Areas: 18

#### **Brief summary/Abstract/Executive summary:**

"This document remplaces the previous EU rRecommendation 2003/878/EC for cancer screeining programs. Few points could be of interest:

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Appropriate data systems are needed to run organised screening programmes

All procedures for collecting, storing, transmitting and analysing data in medical registers and other national and regional official instruments involved must be in full compliance with Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data

The Commission Communication on enabling the digital transformation of health and care in the Digital Single Market, empowering citizens and building a healthier society set out principles to help ensure interoperability with systems for collecting, storing and transmitting data already developed under other initiatives (6), in full compliance with applicable data protection legislation"

**Keywords:** Screening **EUR-Lex** Typology of the retrieved data: Regulation and/or guidelines documents Source: https://eur-lex.europa.eu/legal-content/ES/TXT/HTML/?uri=OJ:C:2022:473:FULL&from=EN **Access details:** 

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Title:	"D10.1: EONS/EPAAC Putting evidence into practice Workshop Evaluation Report"						
	"EAAC Project Lead: Professor Sara Faithfull, Faculty of Health and Medical Sciences, University of Surrey, Guildford, UK.						
Author(s):	Dr Judit Csiszar (EPAAC Project manager, Hungary)						
	EONS Team: Anita Margulies, (EONs board, Switzerland), Expert panel: Dr. Margaret Irwin (USA), Dr Margaret Sneddon (Scotland), Awni Daibes (Belgium), Quinn (UK), Lena Sharp (Sweden)"						
Region/Countr	ry: Europe Year of publication: 2014 Areas: 3,8						

#### **Brief summary/Abstract/Executive summary:**

"Healthcare delivery is becoming more complex and keeping up to date in relation to the evidence is challenging but particularly difficult for nurses in Europe where access to latest research is not always available in the language of that country. Furthermore training is lacking in how to use existing evidence as well as nurses feeling disempowered to make change. Clinical guidelines are one of the factors that lead to quality improvement, as well as enhancing cost effectiveness and job satisfaction they improve patient care (Oborn 2010). Factors influencing sustainability of clinical guidelines is the ability to modify and fit to local context, leadership and workforce attitudes to change as well as education and training for the team on how to use them (Medves et al 2010). The aim of this project was to educate and support nurses and managers to develop and utilise more widely practice based clinical guidelines (CG) and from this improve cancer patient's symptom management and care. The project was conducted in 2 phases of work; phase 1 was translation and production of the Euro PEPs (French, German, Dutch, Slovenian and Croatian), clinical guidance for symptoms commonly managed by nurses. Phase 2 was an implementation phase where the Euro PEPS were disseminated through a supported programme with the use of a self-assessment implementation tool. Evaluation was conducted at baseline and at 3 months from workshop.

The nurses and managers found the workshops helpful in developing skills for implementation of clinical guidelines and working together on a plan of action to implement."

Keywords: "Nurses Education Support"

Typology of the retrieved data: Project documents: deliverables, products, outcomes, from regional, national or European and international projects

Access details: http://www.epaac.eu/images/END/Final Deliverables/D10 EPAAC final report EONS 2014.pdf

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Dissemination Level – Public 84 Version 0.5

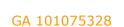




Title:	Tools available to me	Tools available to medicine's developers from the academic sector						
Author(s):	Not specified	Not specified						
Region/Country	Region/Country: Europe Year of publication: Not specified Areas: 3, 8, 10							
Brief summary/	Brief summary/Abstract/Executive summary:							
=	Within this simple infographics, the EMA reports about the tools available to medicine's developers from the academia sector. The pdf is full with practical links to EMA's information regarding this issue							
Keywords:	Keywords: "Academia Support Medicine development"							
Typology of the retrieved data:  Strategic and consultation documents: plans, green papers or white papers  Source: EMA (European Medicines Agency)				(European Medicines Agency)				
Access details:	https://www.ema.europa.eu/en/documents/leaflet/ema-tools-available-medicines-developers-academic-sector_en.pdf							

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Dissemination Level – Public 85 Version 0.5





Title:	II Piano Europeo di	II Piano Europeo di lotta contro el cancro						
Author(s):	Not specified	Not specified						
Region/Country:		Europe	Year of publication:	2023	Areas:	15		
Rrief summary	Rrief summary/Abstract/Executive summary							

"This another very extensive document in which a nuber a acctions and aims related to cancer beat in Europe are described. Among others, the documnent state the importance of an modern approach to fighting cancer, by the use of new technologies, research and innovations focused on cancer prevention and treatment.

It also mentions the necesity of promotion of research and innovation, with an emphasis on the financing of research infrastructure, the use of artificial intelligence and the promotion of collaborations between the health sector, the world academic and other actors to translate scientific knowledge into innovative technologies for the prevention, diagnosis and treatment of cancer.

The importance of the digitalization of health systems and the creation of a common European space for health data is mentioned. This would allow patients to securely access their electronic medical records and share clinical information between doctors and healthcare professionals.

The documente states the importance of initiatives aim at reducing tabaco consumption and food quality control.

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The importance of reducing cancer-related inequialities, related to cancer prevention and access to care throughout the European Union is also stated."

Keywords:	Cancer plan						
Typology of the retrieved data:		Strategic and consultation documents: plans, green papers or white papers	Source:	European Comission			
Access details:		https://documenti.camera.it/Leg19/Dossier/Pdf/I	ES008.Pdf				

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Title:	Plan Europeo de Luc	Plan Europeo de Lucha Contra el Cáncer							
Author(s):	European Comisión	European Comisión							
Region/Country	<b>7:</b>	Europe Year of publication: 2021 Areas: 3,5,7,8,9,10,12,13,14,16							
Brief summary,	Abstract/Executive s	summary:							
"- The document during the comin		out the strategy, coordina	ted at European level, to figl	nt cancer (inclu	ding, among other i	mportant aspects related to prevention, care and research)			
	•	s to be pursued and also we the desired results in the		essary tools, re	esources to be used	l, financing and legal regulation that will be provided and			
Keywords:	Keywords: Cancer Plan, European comision, Funding, Networking againts cancer, Research, Artificial Intelligence, Political support, legal framework.								
Typology of the	retrieved data:	Strategic and consult green papers or white p	ation documents: plans, papers	Source:	Organ	nizations and/or official bodies' publications			
Access details:		https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2021%3A44%3AFIN							

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Title:	-	European Childhood Cancer Organisations' Recommendations following the European Commission's Evaluation of the Legislation for Medicines for Rare Diseases and Children and the launch of the Pharmaceutical Strategy for Europe							
Author(s):	SIOPE	SIOPE							
Region/Count	egion/Country: Europe Year of publication: 2022 Areas: 12, 13, 14, 15, 16,17, 18.								
Brief summar	y/Abstract/Executive s	summary:							
children, as we well as the inecolder medicine	Recommendations from pan-European childhood cancer organisations in response to the European Commission's evaluation of the legislation for medicines for rare diseases and children, as well as the launch of the Pharmaceutical Strategy for Europe. The document highlights the lack of investment and slow pace of innovation in curing paediatric cancers, as well as the inequalities in access to new and essential medicines for children and adolescents with cancer across Europe. It also discusses the adverse long-term side effects caused by older medicines for children and adolescents who survive their cancers. The recommendations aim to address the unmet needs of children and adolescents with cancer in Europe and improve their access to innovative and effective treatments.								
Keywords:	"investment, innovation, paediatric cancers, cross-border clinical research EU Clinical Trials Regulation, multi-stakeholder cooperation"								
Typology of th	e retrieved data:	Strategic and consugreen papers or white	ultation documents: plans, e papers	Source:	We	ebsites, intranets or bulletins			
Access details									





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Press Release Children with cancer still left behind! Childhood Cancer professionals and parents say urgent action is vital following release of the European Commission Title: report on 10 years of the EU Paediatric Regulation Author(s): SIOPE, Unite2Cure network of parents **Region/Country:** Europe Year of publication: 2017 Areas: 12, 13, 14. 15, 16, 17, 18 **Brief summary/Abstract/Executive summary:** Press release from SIOPE and Unite2Cure, two organizations dedicated to improving treatment and access to treatment for children and young people with cancer. The press release discusses the European Commission's 10-year report on the Paediatric Regulation, which recognizes the unmet needs in paediatric oncology but lacks concrete proposals for how to improve the cure for children and adolescents with cancer. The press release calls for urgent action to improve the regulation and highlights concerns voiced by the paediatric cancer community and its supporters. These include the pharmaceutical industry's prioritization of drug development for adult cancer over childhood cancer and the shortcomings of the Regulation's waiver system, which impacts paediatric drug development.

**Keywords:** peadiatric regulation, action, cancer community

Strategic and consultation documents: plans, green papers or white papers

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Source:

Websites, intranets or bulletins

Access details:

Typology of the retrieved data:

https://siope.eu/media/wp-content/uploads/2013/06/1.-PaedReg report PR SIOPE U2C.pdf

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Title:	Optimizing Industry	Optimizing Industry / Academia partnerships						
Author(s):	Accelerate	Accelerate						
Region/Country	gion/Country: Europe Year of publication: 2022 Areas: 6, 8. 12, 13, 14, 15, 7							
Brief summary/	Brief summary/Abstract/Executive summary:							
	This document summarizes the discussions that took place in the ACCELERATE conference 2022 among different stakeholders involved in pediatric cancer research and care regarding several difficulties regarding traslating research to patients.							
Keywords:	Keywords: Preclinical evaluation, clinical trials, licensing							
Typology of the	the retrieved data:  Other (specify)  Source:  Websites, intranets or bulletins					ebsites, intranets or bulletins		
Access details:	https://irp.cdn-website.com/c584cf91/files/uploaded/AC2022 BkO-1 Summary.pdf							

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Dissemination Level – Public 90 Version 0.5





EACR Strategic Plan 2022-2023 Title: Author(s): EUROPEAN ASSOCIATION FOR CANCER RESEARCH (EACR) 3, 8, 12, 13, 14 **Region/Country:** Europe Year of publication: 2022 Areas: **Brief summary/Abstract/Executive summary:** This is the strategic plan of the European Association for Cancer Research. The document establishes 3 main points to focus on the 2022-2023 period: 1. Foster collaboration, 2. organising meetings and education and 3. championing the importance of basic research for cancer Not specified **Keywords:** Strategic and consultation documents: plans, Typology of the retrieved data: Organizations and/or official bodies' publications Source: green papers or white papers https://www.eacr.org/user\_uploads/files/Governance/EACR Strategic Plan 2022-23.pdf Access details:

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Dissemination Level – Public 91 Version 0.5





Title:	LuCE REPORT ON LU	LuCE REPORT ON LUNG CANCER: CHALLENGES IN LUNG CANCER CLINICAL TRIALS						
Author(s):	Lung Cancer Europe	Lung Cancer Europe						
Region/Country	untry: Europe Year of publication: 2018 Areas: 8, 12, 14, 15, 16							
Brief summary/	Abstract/Executive s	ummary:						
	This report by Lung Cancer Europe addresses the main challenges in lung cancer clinical trials. Even though the scope is reduced to a specific type of canceddr, some of the issues raised are transvesal to other cancers research such as lack of funding, public/patient engagement, bucrocracy							
Keywords:	Keywords: Not specified							
Typology of the	retrieved data:	Reports: institutional, statistical	internal, technical or	Source:	Org	anizations and/or official bodies' publications		
Access details:	https://www.lungcancereurope.eu/wp-content/uploads/2021/12/WEB-VERSION-III-LuCE-Report.pdf							

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Dissemination Level – Public 92 Version 0.5





Title:	Annual Report on the ERC activities in 2022							
Author(s):	not listed	not listed						
Region/Country	egion/Country: Europe Year of publication: 2022 Areas: 3, 8							
Brief summary/	Brief summary/Abstract/Executive summary:							
An annual report	An annual report on the ERC activities, prepared by the EU research council about strategy anf governance, achievements, research highlights and similar.							
Keywords:	Keywords: cancer, research, activities							
Typology of the	Typology of the retrieved data:  Reports: institutional, internal, technical or statistical  Source:  Organizations and/or official bodies' publications					nizations and/or official bodies' publications		
Access details:	details: https://op.europa.eu/en/publication-detail/-/publication/3a11d526-ceab-11ed-a05c-01aa75ed71a1							

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Dissemination Level – Public 93 Version 0.5





Title:	European medicines	European medicines agencies network strategy to 2025							
Author(s):	not listed	not listed							
Region/Country	<i>7</i> :	Europe	Year of publication:	2020	Areas:	3, 8, 15			
Brief summary/	Abstract/Executive	summary:							
	•	,	edicines, data analytics, dig f the network and operation		igital transformatio	on, innovation, antimicrobal resistence and other emerging			
Keywords:	Keywords: research, innovation, strategy								
Typology of the	Typology of the retrieved data:  Strategic and green papers of		ation documents: plans, papers	Source:	Organ	nizations and/or official bodies' publications			
Access details:	https://www.ema.europa.eu/en/documents/report/european-union-medicines-agencies-network-strategy-2025-protecting-public-health-time-rapid-change_en.pdf								

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Title:	Real-world evidence	Real-world evidence across the lifecycle of cell and gene therapies. Facilitating patient access.						
Author(s):	not listed	not listed						
Region/Country	<b>7:</b>	Europe Year of publication: 2023 Areas: 3, 8, 15						
Brief summary/	Brief summary/Abstract/Executive summary:							
		<del>-</del>		=	<del>-</del>	re of ATMP in EU. Described proposed stakeholder actions, s are summarized in the document.		
Keywords:	Keywords: real life research, cell and gene							
Typology of the	the retrieved data:  Strategic and consultation documents: plans, green papers or white papers  Source:  Organizations and/or official bodies' publications					nizations and/or official bodies' publications		
Access details:		https://www.eucope.org/wp-content/uploads/2023/02/position-paper-eucope-atmp-rwe-2023-final.pdf						

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Dissemination Level – Public 95 Version 0.5





Title:	EU research and Inno	EU research and Innovation in the fight of Cancer						
Author(s):	not listed	not listed						
Region/Country	<b>/:</b>	Europe	Year of publication:	2021	Areas:	3,8		
Brief summary/	/Abstract/Executive s	ummary:						
A Publication (for	A Publication (formed like a newsletter) about EU Mission Cancer and Horizon Europe about research and Innovation projects and other highlighted initiatives.							
Keywords:	Keywords: research, cancer, innovation, projects							
Typology of the retrieved data:		Other (specify)		Source: Org		Organizations and/or official bodies' publications		
Access details:	https://op.europa.eu/en/publication-detail/-/publication/0af1fb02-69c0-11eb-aeb5-01aa75ed71a1/language-en/format-PDF/source-190199680							

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Dissemination Level – Public 96 Version 0.5



Title:

Author(s):



GA 101075328

Improving the understanding, acceptance and use of oncology-relevant endpoints in HTA body / payer decision-making

Ryll B1, Mikhael J2, Gutierrez Ibarluzea I3, Morgan K4, Ocokoljic M6, Vassal G6, Van Poppel H7, Geissler J8, Gorgoni G9, Bolanos, N10, Milagre, T11

Region/Country: European Year of publication: 2023 Areas: 4, 7, 9, 11, 12, 13, 14, 15. 16

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#### **Brief summary/Abstract/Executive summary:**

This white paper aims to improve the understanding, acceptance, and use of oncology-relevant endpoints in HTA body/payer decision-making. The report identifies current challenges and drawbacks related to the use of overall survival (OS) in clinical trials and articulates the value of oncology-relevant endpoints in addressing these challenges. The report defines the barriers preventing the adoption of oncology-relevant endpoints other than OS, particularly by HTA bodies/payers, and suggests a set of cross-stakeholder and individual stakeholder actions to help ensure timely access to medicines that provide benefits to patients. The findings from this research have been generated through one-on-one interviews with 13 stakeholders, supplemented by a comprehensive literature review. Outcomes from this research were then presented at three round-table discussions with clinicians, patient advocates, and former HTA bodies/payers, where participants debated the benefits and drawbacks of OS, the value of oncology-relevant endpoints, barriers, and potential actions to improve the recognition of these endpoints. The report concludes that stakeholders should work to understand and define the magnitude of treatment benefit required from these endpoints for outcomes to be considered as meaningful by patients, clinicians, HTA bodies/payers, and regulators. Additionally, stakeholders should identify appropriate conduits to disseminate findings in order to drive awareness of oncology-relevant endpoints beyond OS where evidence generation has identified and substantiated their value.

 Keywords:
 endpoints, outcomes

 Typology of the retrieved data:
 Strategic and consultation documents: plans, green papers or white papers
 Source:
 Organizations and/or official bodies' publications

 Access details:
 https://www.efpia.eu/news-events/the-efpia-view/statements-press-releases/improving-the-understanding-acceptance-and-use-of-oncology-relevant-endpoints-in-hta-body-payer-decision-making/

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Dissemination Level – Public 97 Version 0.5





Title:	Challenges in clinical research in Central and Eastern Europe – how can EORTC help?						
Author(s):	European Organisation For Research And Treatment of Cancer (EORTC)						
Region/Country	<b>7:</b>	European2019	Year of publication:	2019	Areas:	2, 8, 13, 14, 16	
Brief summary/	Abstract/Executive	summary:					
In this post from the EORTC a recent published article is discussed regarding the Challenges in clinical research in Central and Eastern Europe. Several challenges are identified in these countries: administrative burden is the main culprit, lack of tiem is also mentioned,							
Keywords: -							
Typology of the	retrieved data:	Other		Source:	Web	osites, intranets or bulletins	
Access details:		https://www.eortc.org/blog/2019/05/02/challenges-in-clinical-research-in-central-and-eastern-europe-how-can-eortc-help/					

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Dissemination Level – Public 98 Version 0.5





Title:	The Heidelberg Man	The Heidelberg Manifesto on European Cancer Research						
Author(s):	German Cancer Research Center (DKFZ)							
Region/Country:		European	Year of publication:	2022	Areas:	5, 8, 9, 12, 13, 14, 16		
Brief summary/	Abstract/Executive s	summary:						
"This Manifesto was prepared and launched under the scope of the 5th Gago Conference on European Science Policy in Heidelberg, Germany on 6 October 2022. This manifest recognizes that the translation of laboratory discoveries into benefits for patients is slow, expensive, and often inefficient, and calls for collective action for developing national and transnational infrastructures that foster cancer research innovation and decrease inequalities. In this document seven high priority themes are outlined: 1. Scope, 2. Scale, 3. Digitalization, 4. Innovation, 5. Public engagement and understanding, 6. Europe-wide collaboration and 7. Commitment and resources"								
Keywords: -								
Typology of the	retrieved data:	Strategic and consultagreen papers or white p	ation documents: plans, apers	Source:	Org	anizations and/or official bodies' publications		
Access details:	https://www.europeancanceracademy.eu/user_uploads/files/publications/Heidelberg_Manifesto_15oct2022_final.pdf							

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Dissemination Level – Public 99 Version 0.5



States that must be standardised across the EU.





Title:	Cancer screening programmes need new foundations – Video of international conference held at MTA HQ						
Author(s):	SAPEA - Science Advice for Policy by European Academies						
Region/Country:		Hungary	Year of publication:	2022	Areas:	1, 8, 12, 13	
Brief summary/Abstract/Executive summary:							

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This webinar includes the conclusions of the evidence report proced under the auspices of the SAPEA consortium (deliverable - Sicence Advice for Policy by Europeans Academies". "The guidelines that determine cancer screening practice today are sometimes two decades old. They are now naturally outdated as new scientific advances are made continuously, and new technical options have been developed. This clearly calls for an update of existing cancer screening strategies." This consortium proposes 3 recommendations: (1) to ensure that existing screening programmes make use of the most up-to-date, cutting-edge science results, and that these programmes are an integral part of the overall cancer treatment strategy; the screening programmes should be extended to all cancers for which these interventions have a good ris-benefit ratio, are financially feasible and the costs are justified in the ligh of the expected out comes; (3) a system of constantly updated recommendations must be developed to ensure a rapid response, and protocols defining screening programmes in the Members

Keywords:	Cancer screening; regulation; knowledge sharing; infraestructure; resources; motivation; communication						
Typology of the retrieved data:		Project documents: deliverables, products, outcomes, from regional, national or European and international projects	Source:	Websites, intranets or bulletins			
Access details: https://mta.hu/english/cancer-screening-programmes-need-new-foundations-video-of-international-conference-held-at-mta-hq-112							

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Title:	Cancer: what are the barriers to research?						
Author(s):	Will West, Catherine Pickering, Kees Melief, John Maher, Jennifer Wheler and Klaas Zuideveld						
Region/Country: International Year of publication: 2023 Areas: 3, 8, 12, 13, 14, 16						3, 8, 12, 13, 14, 16	
Brief summary/	Abstract/Executive	summary:					
"This is an interview by Jim Cornall to some life science company CEOs, CMOs, and chief scientific officers about what are the barriers to cancer research. The main barriers reported by these experts include funding gaps in both private and public sectors, the pressures of industry and academia on certain research topics, regulatory hurdles (failure of regulatory authorities to develop efficient rules for personalised treatmen), decentralised work (vs favor networking and collaborative studies) and the need for incentives.  Many of them share the vision of demonstrating the impact of evidence-based practice, and not just valuing clinical research by publication impact factors.  Finally, reference is also made to the promotion of mentoring opportunities for the development, retention and career progression."							
Keywords: barriers; funding; regulatory; networking, mentoring; incentives; evidence-based practice; career progression.							
Typology of the	retrieved data:	Other		Source:	Webs	sites, intranets or bulletins	
Access details:	https://www.labiotech.eu/in-depth/cancer-barriers-to-research/						

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Access details:





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World Declaration for Research on Cancer Title: World Cancer Research Day. Promoted by AECC, WHO, UICC, EACR, ESMO, NIH, ASCO, Cancer Research UK, AIRC and Dutch Cancer Society Author(s): Year of publication: 8, 9, 10, 12, 14 **Region/Country:** International 2016 Areas: **Brief summary/Abstract/Executive summary:** "The World Declaration for Research on Cancer calls for the active involvement of citizens, entities, institutions and leaders of various areas to join efforts to promote research in order to reduce the number of people who develop cancer and to improve survival rates and quality of life among cancer patients. The delcaration and only proposes 5 goals signataries will have to comply and work for 2025: 1- Increase social awareness and knowledge about the value and impact of cancer research efforts by establishing the World Cancer Research Day 2- Enhance sustainable funding sources for cancer research 3 - Promote international collaboration 4 -Provide training in cancer research. 5- Encourage the development of infrastructures for cancer research" **Keywords:** Organizations and/or official bodies' publications Typology of the retrieved data: Other Source:

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https://www.worldcancerresearchday.com/wp-content/uploads/declarations/World-declaration-fo-cancer-Research-Supporter-V.pdf





Title:	Navigating Breast Ca	Navigating Breast Cancer Research Funding Challenges: EORTC BCG and BIG Insights					
Author(s):	European Organisati	European Organisation For Research And Treatment of Cancer (EORTC) & Breast International Group					
Region/Country:		International	Year of publication:	2023	Areas:	8, 14	
Brief summary/	/Abstract/Executive s	summary:					
U	Webinar organised by the EORTC and Breast Cancer Research Group that was focussed on analysing challenges in research in breast cancer. Several projects were outlined, the lack of funding for non-commercial cancer research, administrative/burocratic issues in the case of public funded research						
Keywords: -							
Typology of the	retrieved data:	Other		Source:	Web	sites, intranets or bulletins	
Access details:		https://www.eortcrese	archfund.org/2023/10/12	/navigating-bre	ast-cancer-resear	ch-funding-challenges-eortc-bcg-and-big-insights/	

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Dissemination Level – Public 103 Version 0.5



Typology of the retrieved data:

Access details:

Other



Organizations and/or official bodies' publications

**World Cancer Report** Title: edited by Christopher P Wild, Elizabeth Weiderpass and Bernard W. Steward Author(s): Year of publication: 2020 3 **Region/Country:** international **Areas: Brief summary/Abstract/Executive summary:** World Cancer Report is an initiative of the International Agency for Research on Cancer (IARC) and is published about every 5 years. Since the inception of World Cancer Report, in 2003, the editorial policy has been to provide a concise, multidisciplinary assessment of current research, made as accessible as possible through a high illustrative content and a minimum of scientific jargon. For every chapter included, authority is achieved in the first instance by engaging experts worldwide, who then face the challenge of presenting information covering broad fields in a few thousand words. All chapters are subject to peer review. **Keywords:** cancer, research, worldwide

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https://ecpc.org/wp-content/uploads/2019/08/ECPC-Immuno-Oncology-Slovenian-Guide.pdf

Source:





Title:	Fundazione Verones	Fundazione Veronesi: Il nostro sostegno alla ricerca scietifica. Finanziamentei 2023					
Author(s):	Not specified	Not specified					
Region/Country	<b>7</b> :	Italy	Year of publication:	2022	Areas:	1,9, 14,15	
Brief summary/	Abstract/Executive s	summary:					
"This document is	s an extensive report v	which presents the 141 re	seachers granted by the fur	dations for the	next years.		
At the end of the document there is section dedicated to two platforms related to research and healtcare. This two platforms relay on the idea that research must be aligned with the new technologies such as Big Data so it is possible to carry out large projects with a strong translational impact, which have concrete possibilities of quickly translating into new solutions for patients."							
Keywords: Foundation; Acknowledgments; Fundings							
Typology of the	retrieved data:	Reports: institutional, statistical	internal, technical or	Source:	Funda	azione Umberto Varonesi	
Access details:	https://fondazioneveronesi.it/uploads/2023/07/21/grant2023.pdf						





Title:	Gli sudi clinicia per il malato oncologico							
Author(s):	M. Bersanelli, C cagn	M. Bersanelli, C cagnazzo, F. De Lorenzo, M Di Maio, E Iannelli, F. Pietrantonio and C. Pinto						
Region/Country	<b>7:</b>	Italy	Year of publication:	2022	Areas:	3, 18		
Brief summary/	Abstract/Executive s	summary:						
This document aims at explain and inform people affected by cancer (patients, family and friends) about clinical trials. It argues there is misinformation problem regarding clinical studies, about their objectives, about how are these conducted and about how to access to these. Other argued problems are: the difficulty about the technical vocabulary, the few time doctors dedicate to speak to their patients and the patients prejudice. All these together build up barriers for the patients to participate in clinical trials.								
Keywords:	Keywords: Clinical Trials; Information							
Typology of the retrieved data:		Other		Source:		IMAC: Associazione Italiana Malati di Cancro, Parenti e Amici		
Access details:		https://www.aimac.it/libretti-tumore/studi-clinici-cancro						

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 106 Version 0.5





Piano Oncologico Nazionale: documento di pianifiazione e indirizzo per la prevenzione el el contrasto del cancro Title: Not specified Author(s): Year of publication: 2021 **Region/Country:** Italy 1 Areas:

#### **Brief summary/Abstract/Executive summary:**

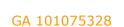
"This is a very extensive document which aims to define a comprehensive approach to cancer, in alignment with the European Beating Cancer Plan 2021, it emphasizes the importance of improving the quality of life for cancer patients and survivors, by leveraging the potential of research an innovation (e.g., genomics for personalized prevention and therapy), and the need to provide cancer frequency data to the National Health Service and the scientific community for research, prevention, care, and program effectiveness evaluation.

There is a section about research communication as an instrument of integration between new and sophisticated technologies and the use of this in the clinical practice in public health.

Another interesting point, within a summary of the strategic lines it is mentioned ""Encourage the development of startups in the m-health sector to improve communication with patients and communication between health centers""."

"Cancer plan **Keywords:** Quality of life" Strategic and consultation documents: plans, Health Ministry, Italian Republic Typology of the retrieved data: Source: green papers or white papers Access details: https://www.salute.gov.it/imgs/C 17 pubblicazioni 3291 allegato.pdf

> Del. 12.1 Recommendations for effective and efficient organization and management of research efforts Dissemination Level - Public 107 Version 0.5





Title:	Integration of palliative care in oncology					
Author(s):	Stein Kaasa					
Region/Country:		Norway	Year of publication:	2021	Areas:	2, 3, 8, 11, 12
Dirich grown and Abertura to Free grating grown and						

#### **Brief summary/Abstract/Executive summary:**

"This presentation by Dr. Stein Kaasa is part of the Palliative Care, Culture and the Clinic symposium. First, it presents how the patient care approach into the cancer clinics could be integrated and what it would imply for the improvement of the quality of life of people living with this disease. In this sense, it indicates that there are resistance to change as well as professional and leadership barriers. For example, with regard to the latter case, if we take into account the perspective of the patient in our consultations, the cost increases, the time is expensive and has an impact on the health system.

Dr Kaasa then mentions the barriers to patient-centred care with respects to mainstream oncology. He then explained the important factors to when thinking of patient-centred care. These barriers are evident, for example it has been systematically demonstrated that PROMS work in clinical studies, however, they are never applied in clinical consultations, not taking this perspective into account in the decision-making process. To this end, it emphasises that it is necessary to influence implementation studies and work on known barriers.

Finally, palliative care requires complex interventions in complex systems, where the barriers to this implementation are even more sources. For this, it is necessary that the whole society, including healthcare providers and health systems are involved, as well as doctors, patients, family members and leadership figures. All these agents must be informed, we have the solutions, the focus should be on how to implement them in the making decision process, as well as, promote multicenter work and develop referential and diagnostic systems."

Keywords:	palliative care; quality	palliative care; quality of life; leadership; patient; barriers; decision-making processes; networking; PROMS					
Typology of the retrieved data:		Other	Source:	Repositories			
Access details:		https://ecancer.org/en/video/9880-integration-of-palliative-care-in-oncology					

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 108 Version 0.5



Access details:



Joint Action JANE GA 101075328

pasientbehandlingen/

Den største utfordringen nå er å integrere kliniske studier som en ordinær del av pasientbehandlingen // The biggest challenge to reach is the integration of clinical Title: studies as an ordinary part of the Patient treatment. Author(s): Baldur Sveinbjørnsson, Daniel Heinrich, Hege Edvardsen & Ketil Widerberg Year of publication: 2020 **Region/Country:** Norway Areas: 8, 11, 13, 14, 16 **Brief summary/Abstract/Executive summary:** "In this webinar experts and politicians discussed options to make clinical trials an integrated part of cancer treatment in Norway. Among the proposed solutions is the promotion of collaborations between industry and the public sector, as is the case with NorCRIN. Also improve build capacity, to make it easier for feasibility, recruitment and approval to be accelerated. It also includes work on improving regulations (e.g. changes to the Biotechnology Act), ethics, funding, infrastructure and competition to combat the barriers to this integration." Barriers; clinical trials; capacity building; regulation; legal; ethic; funding; infrastructure. **Keywords:** Typology of the retrieved data: Websites, intranets or bulletins Other Source:

https://www.lmi.no/2020/05/29/den-storste-utfordringen-na-er-a-integrere-kliniske-studier-som-en-ordinaer-del-av-





GA 101075328

Cancer Control Strategy for Poland 2015-2024 Title: Polish Society of Oncology, Ministry of Health, National Health Fund. Author(s): Poland Year of publication: 2014 **Region/Country:** 12, 14, 16 Areas: **Brief summary/Abstract/Executive summary:** The Cancer Control Strategy for Poland includes a chapter about cancer science and research which states that the achievements in cancer control in recent decades are primarily due to progress in cancer biology research and its translation into clinical practice. The chapter includes the main sources for research funding in Poland and also states strategies to improve the level and quality of the cancer research. In this sense, it includes the following: funding, legal framework, resources, the creation of standards and opportunities of networking with other countries. Funding; networking; legal framework. **Keywords:** Strategic and consultation documents: plans, Organizations and/or official bodies' publications Typology of the retrieved data: Source: green papers or white papers https://www.iccp-portal.org/system/files/plans/Cancer%20Plan%20Poland.pdf Access details:

Joint Action JANE





Title:	Paliativna oskrba odraslih bolnikov z rakom v Sloveniji: temeljni pojmi in priporočila							
Author(s):	different, editors; Ma	different, editors; Maja Ebert Moltara, Marjana Bernot						
Region/Country	y:	Slovenia	Ye	ar of publication:	2020	Areas:	3, 8	
Brief summary,	/Abstract/Executive	summary:						
of palliative care		main aspects	•	-		•	care, summarises the general orientations for the development space standards and competences. Part II introduces a set of	
Keywords:	Keywords: palliative care							
Typology of the	Typology of the retrieved data:  Guidance documents: guidelines on implementation and/or evaluation  Source: Websites, intranets or bulletins						Vebsites, intranets or bulletins	
Access details:								

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts
Dissemination Level – Public 111 Version 0.5





Title:	Državni program ob	Državni program obvladovanja raka 2022-2026					
Author(s):	not listed	not listed					
Region/Country	<i>7</i> :	Slovenia	Year of publication:	2022	Areas:	3, 7, 8, 17, 18	
Brief summary/	Abstract/Executive s	summary:					
	= -		sed on international recom a constitutes an important p		=	sisting of activities, tasks, necessary measures for effective	
Keywords:	Keywords: preventing cancer, cancer research, cancer control						
Typology of the	Typology of the retrieved data:  Strategic and consultation documents: plans, green papers or white papers  Source:  Organizations and/or official bodies' publications					anizations and/or official bodies' publications	
Access details:	https://www.dpor.si/drzavni-program/dpor-2022-2026/						

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts
Dissemination Level – Public 112 Version 0.5





Title:	Letno poročilo Držav	Letno poročilo Državnega programa obvladovanja raka 2022-2026, Leto 2022					
Author(s):	Sonja Tomšič, katarii	Sonja Tomšič, katarina Planosar, Amela Duratović Konjević, janez Žgajnar, Branko Zakotnik					
Region/Country	:	Slovenia	Year of publication:	2023	Areas:	3,8	
Brief summary/	Abstract/Executive s	summary:					
Annual report of review of achieve	o .	ram with data on Cancer	burden, National Cancer P	rogram manag	ement and comm	unication, achieved goals in 2022, EU projects and tabular	
Keywords:	Keywords: cancer burden, cancer goals						
Typology of the	Reports: institutional, internal, technical or statistical  Reports: institutional, internal, technical or statistical  Organizations and/or official bodies' publications						
Access details:		https://www.dpor.si/w	vp-content/uploads/2023/0	02/Letno-poro	cilo-DPOR-2022_fi	<u>inal.pdf</u>	

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts
Dissemination Level – Public 113 Version 0.5







"COMPROMETIDOS CON LA INVESTIGACIÓN EN CÁNCER: Primer informe sobre la investigación e innovación en cáncer en España

"COMMITTED TO CANCER RESEARCH: First Report on Cancer Research and Innovation in Spain"

Author(s): Enric Fuster, Francesco Massucci, Arnau Quinquillà & Alba Velasco

Region/Country: Spain Year of publication: 2018 Areas: 3, 4, 5, 8, 13

Joint Action JANE

# $Brief\,summary/Abstract/Executive\,summary:\\$

This report is the result of the collaboration between the Scientific Foundation of the Spanish Association Against Cancer, the "la Caixa" Banking Foundation (two major national philanthropic foundations), and the Spanish Association for Cancer Research (comprising over 500 professionals dedicated to oncological research). The purpose of this report is to gain a better understanding of the state of cancer research and innovation in Spain, identifying its strengths, weaknesses, as well as areas of opportunity and improvement. Given the pressing need to increase and optimize efforts in cancer prevention, detection, and treatment, with a focus on strengthening scientific research and innovation and expediting their integration into public policies and clinical practice, the report highlights a significant talent loss in Spain. Therefore, policies aimed at attracting talent should strive to internalize and promote greater integration and multidisciplinarity in cancer research. This can be achieved by facilitating cross-training and transitions between fundamental, translational, and clinical research and among various disciplines, including nanotechnology, photonics, bioinformatics, and other scientific and technological fields, as well as epidemiology, economics, public policy, nursing, and healthcare professions, given the current challenges in achieving this level of integration.

 Keywords:
 Talent; translational research; multidiciplinarity; clinical research; integration.

 Typology of the retrieved data:
 Reports: institutional, internal, technical or statistical
 Source:
 Organizations and/or official bodies' publications

 Access details:
 https://www.contraelcancer.es/sites/default/files/content-file/Informe-investigacion-cancer.pdf

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 114 Version 0.5





GA 101075328

Joint Action JANE

Title:	Estrategia de investigación e innovación er	Estrategia de investigación e innovación en Salud 2022-2025 (Gobierno Vasco)					
Author(s):	Departamento de Salud, Gobierno Vasco	Departamento de Salud, Gobierno Vasco					
Region/Country	Spain	Year of publication:	2022	Areas:	3, 8, 10, 11, 12, 14, 16		

## **Brief summary/Abstract/Executive summary:**

"This document is not specific to cancer, but to the Health Innovation and Research Strategy in the Basque Country. A SWOT analysis was carried out in order to prepare it and plan strategies and lines of action. One of the weaknesses identified was the lack of integration of research in the health system. Therefore, taking into account the diagnosis of the situation and the internal and external analysis in the operational implementation of the Mission, Vision and Values, it has been defined in Axis 1 of Coordination and Integration for the period 2022-2025 to identify new models for the integration of research in the Osakidetza Health System, generating two strategic lines. The first focuses on the model of integration of research with care and the second on the transfer and adoption of research results in the care and business system.

There is a perception that academic research is not sufficiently aligned with clinical practice. In general, there is considered to be a clear disconnect between care and academia. The creation of mixed research groups could be one solution, although others are being considered, such as providing incentives for a professional research career (curricular merit), creating protocols for access to clinical data and samples, and facilitating the evaluation of the results of research and innovation activities.

The need to define a management model that facilitates the scaling up, translation and implementation of priority R&D&I results in health care practice is also highlighted, as well as the possible funding of actions to support this translation."

	Keywords:		ategic plan; collaboration; recognition; scientific career; funding; translation						
	Typology of th	e retrieved data:	Strategic and consultation documents: plans, green papers or white papers	Source:	Organizations and/or official bodies' publications				
Access details: https://www.euskadi.eus/contenidos/informacion/estrat invest innov 2022 2025/es def/adjuntos/estrategia invest innov es.pdf									

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 115 Version 0.5





Libro blanco de la investigación en enfermería en Euskadi Title:

Author(s):

Juani Argomaniz, Sendoa Ballesteros, Encarnación Betolaza López de Gámiz, Mª Angeles Cidoncha Moreno, Lucía Elosegui Itxaso, Irrintzi Fernández Ahedo, Aintzane Orkaizaguirre, Javier Ortiz de Elguea Diaz, Janire Portuondo Jimenez, Fernando Ramos Peña, Vanesa Regúlez Campo, Sheila Sánchez Gómez, Jaione Santiago Garín, Ainhoa Ulibarri Ochoa, Gorka Vallejo de la Hoz, Sergio Yuste Muñoz, Jagoba Zarandona Calvo, Verónica Tíscar-González, Joan Blanco Blanco, Teresa Moreno Cascabas, Adolfo Romero Ruiz.

2, 3, 4, 5, 9, 10, 11, 14 Spain Year of publication: 2021 **Region/Country:** Areas:

#### **Brief summary/Abstract/Executive summary:**

"This document recognises the need to improve the integration of evidence-based practice at all levels of scope of the Public Health System, as well as to ensure the transfer of results and applicability/impact in the care of research. Subsequently, proposals are presented for the improvement of the promotion of research in the health field in nursing in the Basque Country.

These actions are presented at different organizational levels, such as in the care units, health organisations, Department of Health of the Government and even from the initial training in university studies.

Among these improvement proposals are the recognition of merits related to research training, to encourage and properly assess scientific production, to facilitate reconciliation with care practice (economic and time means), continuous training in research methodology, to facilitate assistance to specialised training and congresses, as well as the release of tasks and the creation of specific research places.

It should be noted that the Osakidetza 2017-2020 plan assumes the rest of integrating the research and innovative activity, with the assistance and teaching work, through the articulation of the different structures, processes, responsibilities and functions integrated within the global R+D."

**Keywords:** integration; evidence-based practice; impact; recognition; merits; training; mentoring; congresses; research; nurse.

Strategic and consultation documents: plans, Websites, intranets or bulletins Typology of the retrieved data: Source: green papers or white papers

https://www.bjoaraba.org/wp-content/uploads/2021/08/Libro-Blanco-de-Investigacio%CC%81n-Enfermeri%CC%81a-Digital.pdf Access details:

> Del. 12.1 Recommendations for effective and efficient organization and management of research efforts Dissemination Level - Public 116 Version 0.5





Title:	Informe de la evalua	Informe de la evaluación de la estrategia de Cuidados Paliativos del Sistema Nacional de Salud					
Author(s):	Carlos Peralta Galleg	Carlos Peralta Gallego, Sonia Peláez Moya, Carolina García González, Antonio Sacristán Rodea. Ingrid Bullich Marín. Luís Miguel García Aparicio.					
Region/Country:		Spain	Year of publication:	2022	Areas:	8 Resources 9 Dissemination 13 Policy and regulatory	

## **Brief summary/Abstract/Executive summary:**

The evaluation of the SNS Palliative Care Strategy aims to assess and/or determine the degree of compliance with the established objectives, through the collection of the results of the established indicators and evaluation criteria. So Likewise, based on these results and to the extent possible, a proposal is made of conclusions on "priority lines of action to reinforce or implement." The document of indicators and other evaluation criteria of the ECP-SNS proposed mainly indicators on the availability of certain resources, as well as the care process, also taking into account the feasibility of obtaining each one of them depending on the availability of homogeneous and standardized sources. The objective of this document is to present the results obtained from the evaluation of the Palliative Care Strategy in Spain, for the period from 2015 to 2019. This document describes the difficulties to develop research in palliative (including cancer palliative care)"

	Keywords:	Palliative care, politica	ative care, political regulation					
Typology of the retrieved data:  Reports: institutional, internal, technical or statistical  Source: Organizations and/or official bodies' publications					Organizations and/or official bodies' publications			
Access details: <a href="https://isanidad.com/wp-content/uploads/2023/01/informe-evaluacion-estrategia-cuidados-paliativos-SNS-2022.pdf">https://isanidad.com/wp-content/uploads/2023/01/informe-evaluacion-estrategia-cuidados-paliativos-SNS-2022.pdf</a>					rategia-cuidados-paliativos-SNS-2022.pdf			

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 117 Version 0.5





GA 101075328

Joint Action JANE



Title:	Guía GEICAM de práctica clínica para el diagnósitco y tratemiento del cáncer de mama metastásico ("GEICAM clinical practice guide for the diagnosis and treatment of metastatic breast cancer")						
Author(s):	Guía GEICAM de práctica clínica para el diagnósitco y tratemiento del cáncer de mama metastásico ("GEICAM clinical practice guide for the diagnosis and treatment of metastatic breast cancer")						
Region/Country: Spain Year of publication: 2015 Areas: 8, 14, 15						8, 14, 15	
Brief summary/Abstract/Executive summary:							

"The objective of this GEICAM Clinical Practice Guide for the Diagnosis and Treatment of Metastatic Breast Cancer is to serve as an instrument to improve clinical management of women with metastatic breast cancer, which in Spain is usually decided in specialized care by specialists in Medical Oncology, in addition to facilitating relevant information on this matter for other health professionals who care women with this disease, patients and their families. In the intruduction this Clinical Practice Guide states how complex healthcare practice is becoming increasingly complex due to multiple factors, among which the exponential increase in scientific information is one of the most relevant. Addressing quality improvement in clinical practice requires permanent updating of professionals and making available to them the appropriate tools that facilitate the performance of their functions and decision making. In this sense, the Clinical Practice Guidelines (CPG) are a set of "recommendations systematically developed to help professionals and patients make decisions about the most appropriate healthcare, and select diagnostic options therapeutics that are most appropriate when addressing a health problem or condition specific clinic" (GPC Methodological Manual 2007). This document also highlight the importance of the working group (Grupo de trabajo de Enfermedad meastásica del Grupo GEICAM de Investigación en Cáncer de Mama) as well as the collaboration of other experts. Also the economical contribution of several Pharma Laboratories (AstraZeneca, Celgene, Novarits y Roche) is mentioned."

Keywords: Clinical Practice Guide; Metastatic Breast Cancer; Diagnostic and treatment

Typology of the retrieved data:

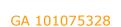
Guidance documents: guidelines on implementation and/or evaluation

Source: GEICAM

https://www.geicam.org/en/medical-research-professionals/research/clinical-practice-guides

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 118 Version 0.5





Title:	Plan Oncológico de Euskadi						
Author(s):	Not specified						
Region/Country	on/Country: Spain Year of publication: 2018-2023 Areas: 9						
Brief summary	Rrief summary/Abstract/Fyecutive summary						

"Euskadi Oncology Plan 2018-2023 defines the areas of action in cancer care and has the objective of improving cancer survival, one of the main health problems of our society. The document, which is aligned with the principles that inspire the 2013-2020 Health Plan, has been prepared by the Department of Health of the Basque Government with the advice of groups of experts and health professionals involved in the care of cancer patients and their families.

In general terms, the Plan proposes a care model, with a multidisciplinary approach, humanized treatment that addresses the global needs of patients and reduces diagnosis times and concentrates the most complex interventions in reference units that allow for pooling experience. necessary.

The Oncology Plan also delves into the development of personalized or precision medicine (MPP), which allows patients to be offered individualized treatment based on their characteristics and those of the tumor they suffer from, with the support of a computer system that includes in the Electronic Medical Record all the information about the oncological process, from the treatments received to the quality of life of the patient, so that it can be useful in decision making.

All of this accompanied by the deployment of an innovation strategy that seeks to involve technology companies in the Basque Country in the development of new cancer diagnosis and treatment tools, and the permanent commitment to intersectoral health promotion and prevention strategies."

Keywords:	Regional oncology plan					
Typology of th	e retrieved data:	Strategic and consultation documents: plans, green papers or white papers	Source:	Health Department of the Basque Country		
Access details:		https://www.iccp-portal.org/system/files/plans/p	olan-oncologico-euskadi-20	118-2023.pdf		

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts Dissemination Level - Public 119 Version 0.5





GA 101075328 Joint Action JANE

Title:	Medical information	Medical information from GEPAC							
Author(s):	Not specified								
Region/Country	:	Spain	Year of publication:	2020	Areas:	7, 9, 15			
Brief summary/	Abstract/Executive s	summary:							
destinated to prof	"This website states the problem about the quality of the information that cancer patient have access to. Sometimes this is out of date, erroneous or not appropriate, but sometimes it is destinated to professionals and thus, difficult to understand for patients. All this apart from the continuous development of the area.  Taking all this together GEIPAC aims at offering medical information to patients, using more accessible language but with quality hallmark. Thus, GEIPAC offers a number of activities to inform patients and make all this medical world easier for them."								
Keywords:	Language; Patients; W	orkshops; Documents							
Typology of the	retrieved data:	Guidance documer implementation and/or	0	Source:		AC (Grupo Español de PAcientes con Cancer, Spanish Group ncer Patients)			
Access details:		https://www.gepac.es/	/informacion-medica/						





GA 101075328

e:	Innovación sanitaria para salir reforzados de la crisis de la COVID-19
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Joint Action JANE

Author(s):

Title

Jesús María Fernández Díaz, Antón Costas, Joan X Comellas, Laia Arnal Arasa, Nathalie Moll, Eduardo Díaz-Rubio, José Luis Fernández, Álvaro Hidalgo, David Cantarero Prieto, Jospe Pomar, Santiago Rabanal, Pedro Luis Sánchez, Rafael Bengoa, Patricia Arratibel,

Region/Country: Spain Year of publication: 2020 Areas: 1, 3, 4, 6, 7, 8, 11, 12, 13, 14, 15, 17, 18.

# **Brief summary/Abstract/Executive summary:**

This document reflects the reflection of experts in economics, research, clinical and industry on the vulnerabilities and deficiencies, and strengths and potential of our health care systems after the COVID-19 pandemic. It aims to evaluate and take advantage of the social, economic and technological changes that are taking place and thus materialize the virtuous circles between health, innovation, economic growth and human development.

Keywords: Innovation, Integration, Motivation, Political regulation, Research promotion, Research funds, Economics, Development

Typology of the retrieved data: Books that report empirical information Source: Websites, intranets or bulletins

Access details: https://www.farmaindustria.es/web/wp-content/uploads/sites/2/2021/02/Libro-Innovacio%CC%81n-sanitaria-WEB.pdf

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 121 Version 0.5







21-JA-IBA Joint Action JANE GA 10107532

Title: Estrategia Española de Ciencia, Tecnología e Innovación 2021-2027

Author(s): Ministry of Science and Innovation

Region/Country: Spain Year of publication: 2020 Areas: 3, 4, 6, 7, 8, 12, 13, 14, 17, 18.

## **Brief summary/Abstract/Executive summary:**

This document of the Spanish Science, Technology and Innovation Strategy 2021-2027 (EECTI 2021-2027) is the basic instrument to consolidate and reinforce the Science, Technology and Innovation System (SECTI) in the next seven years. It is specifically designed to facilitate the articulation of our policy of R+D+I with the policies of the European Union, taking into account the approved regulations or ongoing, in order to take advantage of the synergies between the programs in the best possible way. In this aspect, the strategy adds elements that also aim to promote the maximum coordination between State and Regional planning and programming. The national strategic sectors include the areas of health; culture, creativity and inclusive society; security; digital world, industry, space and defense; climate, energy and mobility; and food, bioeconomy, natural resources and environment.

Keywords: Science, Technology, Innovation, research promotion, political regulation,

Typology of the retrieved data:

Strategic and consultation documents: plans,

green papers or white papers

Source:

Organizations and/or official bodies' publications

Access details: https://www.ciencia.gob.es/Estrategias-y-Planes/Estrategias/Estrategia-Espanola-de-Ciencia-Tecnologia-e-Innovacion-2021-2027.html

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 122 Version 0.5





Title:	Oncología de Precisión. Situación en España y recomendaciones para un Plan de Acceso a los Biomarcadores						
Author(s):	Miguel Ángel Calleja, Pilar Garrido, José Javier Gomez Román, Javier Hernández Losa, Joaquín Martínez, Salvador Peiró, Ruth Vera, Jorge Aboal Viñas, Alfonso Aguarón, Olga Delgado, Enriqueta Felipe, Ramón García-Sanz, Iñaki Gutiérrez-Ibarluzea, Adrián Llerena, Rubén Moreno, José Martínez Olmos, Francisco Valero Bonilla.						
Region/Country:		Spain	Year of publication:	2021	Areas:	3, 5, 7, 8, 13, 14, 17, 18.	
Brief summary/Abstract/Executive summary:							

The objective of this document is to stablish the foundations for designing and specifying a common framework for addressing precision oncology at the national level. This common framework should not only determine the appropriate process to recognize those biomarkers and medications that favor obtaining better results for cancer patients, but also determine the form and deadlines for the incorporation of these medications and their companion diagnostics in the Common Portfolio of SNS Services. An adequate common framework for approaching these innovative technologies will allow us to recognize the value of response-predicting biomarkers and associated medications to improve health outcomes in cancer and favor homogeneous responses by the SNS to the same health needs.

Keywords: Precision medicine, cancer, biomarker, predictive biomarker							
Typology of the	e retrieved data:	Guidance implementa	documents: ition and/or evalu	guidelines uation	on	Source:	Organizations and/or official bodies' publications
Access details:		https://sehb los-biomarca	**	es/informes/12	4842-	oncologia-de-precision-situ	acion-en-espana-y-recomendaciones-para-un-plan-de-acceso-a-

Del. 12.1 Recommendations for effective and efficient organization and management of research efforts

Dissemination Level – Public 123 Version 0.5





Title:	SEOM crea el Observatorio de Medicina de Precisión en Oncología para evaluar su implementación en España						
Author(s):	Spanish society of m	Spanish society of medical oncology					
Region/Country:		Spain	Year of publication:	2022	Areas:	9, 11, 17, 18	
Brief summary/	Brief summary/Abstract/Executive summary:						
This article describes how the precision medicine observatory of the Spanish Society of Medical Oncology will analyze the use of genetic studies and biomarkers that are necessary for the selection and use of the most innovative treatments against cancer.							
Keywords:	Keywords: Precision medicine, cancer, biomarker, targeted therapy, molecular biology, research promotion.						
Typology of the	retrieved data:	Other		Source:	Org	ganizations and/or official bodies' publications	
Access details:	Access details: https://seom.org/images/revista 138 pub.pdf						

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Dissemination Level – Public 124 Version 0.5





NETWORKS OF EXPERT

Title: Cancer Strategy of the National Health System. Update approved by the Interterritorial Council of the National Health System, on February 24, 2021.

Author(s): Ministry of Health

Region/Country: Spain Year of publication: 2021 Areas: 3, 4, 7, 8, 9, 13, 17. 18

Joint Action JANE

## **Brief summary/Abstract/Executive summary:**

This document includes the main strategies in cancer in the Spanish national health system proposed for 2022, which include: the development of the European Code against Cancer, the approval by the Interterritorial Council of population screening for cervical cancer, along with breast and colorectal cancer, the progressive extension of the multidisciplinary care model, The need to improve access to diagnostic tests, precision medicine, the model of European reference centers together with that of SNS Reference Centers (CSUR) in Spain as a key approach to improve clinical results in rare tumors, the care model in pediatric cancer, the development of a cooperative model based on healthcare networks between professionals and centers, quality of life, psychological care and assessment of the needs of patients who have survived cancer and research.

**Keywords:** Cancer Plan, Networking against cancer, Research, Political support, legal framework.

Typology of the retrieved data:

Strategic and consultation documents: plans, green papers or white papers

Source:

Organizations and/or official bodies' publications

Access details: https://www.sanidad.gob.es/organizacion/sns/planCalidadSNS/pdf/ESTRATEGIA EN CANCER DEL SNS.pdf

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Dissemination Level – Public 125 Version 0.5







-JA-IBA Joint Action JANE GA 1010753

Title:	Estrategia de Salud Pública 2022						
Author(s):	Ministry of Health						
Region/Country:		Spain	Year of publication:	2022	Areas:	1,2,7,9,12,13,16	

## **Brief summary/Abstract/Executive summary:**

The document includes the main ""guidelines"" of the Public Health Strategy (ESP) proposed for 2022. This strategy is within the context of the guidelines contained in the Cancer Strategy of the National Health System and aligned with the objectives of the European Plan of Fight against Cancer. Among other aspects, the importance of carrying out public health research mainly through ISCIII (CIBER Centers) and CSIC is highlighted. In this sense, the structures, HR and financing methods available and necessary are described. The great relevance of carrying out adequate communication, promotion, training and legislation in this environment is also suggested. To achieve this, alliances and collaborations with "all sectors involved" are undoubtedly essential. Finally, a proposal of indicators and specific actions to be carried out is made... to try to achieve the desired objectives and be able to measure the results achieved."

	Keywords: National Strategy, Public Health, Public Research, Communication, Education, Networking/Collaboration.						
	Typology of th	e retrieved data:	Strategic and consultation documents: plans, green papers or white papers	Source:	Organizations and/or official bodies' publications		
Access details: Estrategia_de_Salud_Publica_2022Pendiente_de_NIPO.pdf (sanidad.gob.es							

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Dissemination Level – Public 126 Version 0.5



Title:

Author(s):



Seguimos luchando contra la desigualdad en cancer. Informe Anual 2021 Asociación Española contra el Cáncer (AECC) Year of publication: 2021 1,8,9,12,13,14 **Region/Country:** Spain Areas:

## **Brief summary/Abstract/Executive summary:**

The document contains a description of the association's activity, achievements and objectives for the coming years. In addition, epidemiological information about our environment is provided. The promotion and support for cancer research and the attempt to guarantee equitable access to this research and the best available treatments are highlighted. The work of disseminating to society the importance of research in this field, the need to provide funds (public and private financing) and coordination of efforts is described. Finally, the report of activities carried out by the group in the different regions of our country, the funds obtained (sources) and the available resources belonging to the association are also presented."

Research promotion, Research funds, AECC **Keywords:** Reports: institutional, internal, technical or Typology of the retrieved data: Organizations and/or official bodies' publications Source: statistical https://transparencia.contraelcancer.es/wp-content/uploads/2022/01/2021-memoria-contra-el-cancer-informe-anual.pdf Access details:

Joint Action JANE

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Title:	Los institutos de inve	Los institutos de investigación, adalides de la medicina del futuro en el mundo						
Author(s):	Gaceta Médica	Gaceta Médica						
Region/Country	y:	Spain	Year of publication:	2023	Areas:	2,3,8,9,12,15		
Brief summary,	Brief summary/Abstract/Executive summary:							
This document describes some of the structures (institutes) available in our country dedicated to trying to bring together assistance and research. Additionally, the resources available at some of these centers are listed. Certain aspects that make the reconciliation of both activities difficult are also mentioned."								
Keywords:	Keywords: Research institutes							
Typology of the	retrieved data:	Other		Source:		ecialist newspaper report		
Access details:	https://gacetamedica.com/investigacion/los-institutos-de-investigacion-adalides-de-la-medicina-del-futuro-en-el-mundo/							

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Dissemination Level – Public 128 Version 0.5





Title:	Fernando Calvo: «Investigar el cáncer me parece un problema científico fascinante y sumamente complejo que supone un desafío diario»							
Author(s):	ASIECA							
Region/Country	y:	Spain	Year of publication:	2019	Areas:	1,3,7,9,12-14		
Brief summary/	Brief summary/Abstract/Executive summary:							
dedicating yourse	In this interview with a researcher from a public research institute in Spain, belonging to a national researcher's association (ASIECA), we talk about the reasons and motives why dedicating yourself to research can be very interesting. On the other hand, several factors are listed (financing, political will, legal regulation, etc) that make it difficult to carry out this research work in Spain.							
Keywords:	Keywords: Basic research, motivation, political regulation, research support							
Typology of the	retrieved data:	Other		Source:	Inter	view		
Access details: https://www.aseica.es/fernando-calvo-investigar-cancer-me-parece-un-problema-cientifico-fascinante-y-sumamente-complejo-que-suun-desafio-diario					cientifico-fascinante-y-sumamente-complejo-que-supone-			

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Title:	Scientific annual rep	Scientific annual report 2021 SJD-IRSJD						
Author(s):	Sant Joan de Déu Hospital- Institut de Recerca Sant Joan de Déu							
Region/Country:		Spain	Year of publication:	2021	Areas:	3, 5, 8, 17		
Brief summary/	Abstract/Executive s	summary:						
Scientific annual	report of SJD-PCCB ins	titution, including the Tra	nslational Molecular Onco	logy Laboratory	7.			
Keywords:	Keywords: scientific report, translational							
Typology of the	retrieved data:	Reports: institutional, statistical	internal, technical or	Source:	Or	ganizations and/or official bodies' publications		
Access details:	Access details: https://www.irsjd.org/media/upload/domain_3/pdf/irsjd-2021-memoria_1658309521.pdf							

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Dissemination Level – Public 130 Version 0.5





Title:	Memoria Solidiaria 2	Memoria Solidiaria 2020						
Author(s):	Sant Joan de Déu Hos	Sant Joan de Déu Hospital						
Region/Country	:	Spain	Year of publication:	2020	Areas:	15, 17, 18		
Brief summary/	Abstract/Executive s	summary:						
Annual report of o	Annual report of donations and no competitive funding to different projects (research, clinical care) within Sant Joan de Déu Hospital							
Keywords:	donations, funding							
Typology of the	retrieved data:	Reports: institutional statistical	internal, technical or	Source:	Orga	nizations and/or official bodies' publications		
Access details:		https://www.sjdhospit	albarcelona.org/sites/defau	ılt/files/conten	t/file/2022/08/3	1/11/memoria-solidaria-2020-cast-cifras.pdf		

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Dissemination Level – Public 131 Version 0.5





Title:	Interview								
Author(s):	La Caixa	La Caixa							
Region/Country	y:	Spain	Year of publication:	2022	Areas:	1,3, 9, 13, 17, 18			
Brief summary,	/Abstract/Executive s	summary:							
Interview about the challenges encountered in developmental cancer, including research and translation to clinical care									
Keywords:	challenges								
Typology of the retrieved data:		Other		Source:	Web	osites, intranets or bulletins			
Access details:		https://caixaresearch.o	org/es/debates-caixaresear	ch-cancer-infan	<u>ntil</u>				





Title:	Memoria 2022 Cris contra el Cáncer						
Author(s):	Cris contra el Cáncer						
Region/Country	:	Spain	Year of publication:	2022	Areas:	6, 8, 9, 10, 11, 12, 14, 15, 17, 18	
Brief summary/	Abstract/Executive s	summary:					
Annual report of f	funded projects by Cris	s contra el Cáncer Founda	tion				
Keywords:	Keywords: funding						
Typology of the	retrieved data:	Reports: institutional, statistical	internal, technical or	Source:	Org	ganizations and/or official bodies' publications	
Access details:		https://criscancer.org/	wp-content/uploads/2023,	/09/PDF-COMI	PLETO-MEMO-CF	RIS-21-R.pdf	

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Dissemination Level – Public 133 Version 0.5





GA 101075328

Joint Action JANE

Memoria 2021 Asociación Española Contra el Cáncer Title: Author(s): Asociación Española contra el Cáncer Year of publication: **Region/Country:** Spain 2021 6, 8, 9, 10, 14, 15, 17, 18 Areas: **Brief summary/Abstract/Executive summary:** Annual report of funded projects by Asociación Española contra el Cáncer funding **Keywords:** Reports: institutional, internal, technical or Organizations and/or official bodies' publications Typology of the retrieved data: Source: statistical  $\underline{https://transparencia.contrael cancer.es/wp-content/uploads/2022/01/2021-memoria-contra-el-cancer-informe-anual.pdf}$ Access details:

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Dissemination Level – Public 134 Version 0.5





"COMPROMETIDOS CON LA INVESTIGACIÓN EN CÁNCER: Primer informe sobre la investigación e innovación en cáncer en España //

"COMMITTED TO CANCER RESEARCH: First Report on Cancer Research and Innovation in Spain""

Author(s): Enric Fuster, Francesco Massucci, Arnau Quinquillà & Alba Velasco

Region/Country: Spain Year of publication: 2018 Areas: 3, 4, 5, 8, 13

Brief summary/Abstract/Executive summary:

This report is the result of the collaboration between the Scientific Foundation of the Spanish Association Against Cancer, the "la Caixa" Banking Foundation (two major national

This report is the result of the collaboration between the Scientific Foundation of the Spanish Association Against Cancer, the "la Caixa" Banking Foundation (two major national philanthropic foundations), and the Spanish Association for Cancer Research (comprising over 500 professionals dedicated to oncological research). The purpose of this report is to gain a better understanding of the state of cancer research and innovation in Spain, identifying its strengths, weaknesses, as well as areas of opportunity and improvement. Given the pressing need to increase and optimize efforts in cancer prevention, detection, and treatment, with a focus on strengthening scientific research and innovation and expediting their integration into public policies and clinical practice, the report highlights a significant talent loss in Spain. Therefore, policies aimed at attracting talent should strive to internalize and promote greater integration and multidisciplinarity in cancer research. This can be achieved by facilitating cross-training and transitions between fundamental, translational, and clinical research and among various disciplines, including nanotechnology, photonics, bioinformatics, and other scientific and technological fields, as well as epidemiology, economics, public policy, nursing, and healthcare professions, given the current challenges in achieving this level of integration.

 Keywords:
 Talent; translational research; multidiciplinarity; clinical research; integration.

 Typology of the retrieved data:
 Reports: institutional, internal, technical or statistical
 Source:
 Organizations and/or official bodies' publications

 Access details:
 https://www.contraelcancer.es/sites/default/files/content-file/Informe-investigacion-cancer.pdf

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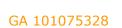
Dissemination Level – Public 135 Version 0.5





	Manifest: ¡Queremos inventar nosotros, por favor!								
We want to invent, please!									
Author(s):	ASOCIACIÓN ESPAÑOLA DE INVESTIGACIÓN SOBRE EL CÁNCER (ASEICA)								
Region/Country	on/Country: Spain Year of publication: 2019 Areas: 13,14								
Brief summary/	Abstract/Executive s	summary:							
	The text denounces the decline of Spain's scientific research system, which began during the past decade's economic crisis. It highlights the decrease in funding for research and development (R&D) and bureaucratic difficulties cancer researchers and innovators face								
Keywords:									
Typology of the	retrieved data:	Other		Source:	Web	osites, intranets or bulletins			
Access details:	https://www.aseica.es/wp-content/uploads/2020/01/MANIFIESTO-POR-LA-CIENCIA-nuevo-logo.pdf								

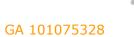
Del. 12.1 Recommendations for effective and efficient organization and management of research efforts Dissemination Level - Public 136 Version 0.5





	POSICIONAMIENTO ASEICA-MED SOBRE EL COLECTIVO MÉDICO-INVESTIGADOR								
Title:	ASEICA-MED'S POS	MEDICAL-I	RESEARCH	COMMUNITY					
Author(s):	ASOCIACIÓN ESPAÑOLA DE INVESTIGACIÓN SOBRE EL CÁNCER (ASEICA)								
Region/Country	Region/Country: Spain Year of publication: 2023 Areas: 2, 4, 8, 10, 13, 14							2, 4, 8, 10, 13, 14	
Brief summary/	/Abstract/Executive	summary:							
This report states the position of ASEICA on the clinician researcher in Spain. The report highlights several difficulties faced and forwards two key proposals to improve research: 1. To establish the category of "Medical-Research Staff" in the National Health System and 2. Recognition of research activity as a merit in the National Health System.									
Keywords: -									
Typology of the	retrieved data:	Reports: ir statistical	istitutional,	internal,	technical o	Source:		Organ	nizations and/or official bodies' publications
Access details:		https://ww	w.aseica.es/	wp-conten	t/uploads/20	023/09/POSI	CIONAMIENTO:	-ASEICA-	-Sep_version-final_maquetado_12adhesiones260923.pdf







Title:										
	"For a long-term Str	"For a long-term Strategy for science and innovation in Spain"								
Author(s):	ASOCIACIÓN ESPAÑOLA DE INVESTIGACIÓN SOBRE EL CÁNCER (ASEICA)									
Region/Countr	Region/Country: Spain Year of publication: 2020 Areas: 6, 8, 12, 13, 14, 16									
Brief summary	/Abstract/Executive s	summary:								
Research and In	This report by the Spanish Cancer Research Organisation (ASEICA) and the spanish association of biocompanies (ASEBIO) addresses several measures to the various challenges of Research and Innovation in Spain in the Biomedical field in general. These measures are divided in two separate categories: 1. measures to strengthen basic and translational research and 2. measures to strengthen innovation and transition to a sustainable economy.									
Most of the challenges and measures identified in this report apply to cancer research and are many times ignored. The report puts a particular focus on the point of view of companies and public-private collaboration, proposing measures to promote that research and innovations translates to the industrial tissue.										
Keywords: -										
Typology of the	Strategic and consultation documents: plans, green papers or white papers  Strategic and consultation documents: plans, green papers or white papers  Source:  Organizations and/or official bodies' publications									
Access details:		https://www.aseica.es/	wp-content/uploads/2020	/11/201112-E	strategia-a-largo-p	olazo-ciencia-e-innovacion-Espan%CC%83a.pdf				





Title:	Regulatory guide for	Regulatory guide for ATMPs: a generic process guide from the pre-clinical to clinical development phase for ATMPs							
Author(s):	project members: Ha	project members: Hanna Bengter, Eva Bondesson, Catherine Concaro, and others							
Region/Country	n/Country: Sweden Year of publication: 2017 Areas: 3								
Brief summary/	/Abstract/Executive s	ummary:							
Useful informatio	Useful information, guide and insights throughout ATMP development process.								
Keywords: ATMP development, regulation, guideline									
Typology of the retrieved data: Good practices				Source:	Wel	bsites, intranets or bulletins			
Access details:	https://www.karolinska.se/49961f/contentassets/579a2e9e16484675b3a3e05eb35cbc36/generisk-processkarta arbetspaket 1 ver0.1.pdf								

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Dissemination Level – Public 139 Version 0.5





Title:	MORECare project	MORECare project							
Author(s):	Catherine Evans, Ire	Catherine Evans, Irene Higginson							
Region/Country	y:	UK	Year of publication:	2013	Areas:	3, 5, 8			
Brief summary,	/Abstract/Executive s	ummary:							
individuals near	"The Methods for Researching End of Life Care Capacity project (MORECare) aimed to identify, appraise and synthesise 'best practice' methods to determine how best to include individuals near to death with limited, fluctuating, diminishing or lack of capacity in research on end-of-life care (EoLC). Funded by Marie Curie (September 2011-March 2013) Dr Catherine Evans, Principal Investigator								
focusing on mana	This progressed the project MORECare that developed evidence-based guidance on the best methods for the design and conduct of research on EoLC to further knowledge in the field, focusing on managing missing data and attrition, outcome measurement, ethical issues, mixed methods and health economics. Funder by the Medical Research Council (November 2009-January 2021), Professor Irene Higginson. Principal Investigator"								
Keywords: Palliative care, terminal care, research design, methods, evaluation, ethics, decision-making									
Typology of the	retrieved data:	Other	Source:		ite				
Access details:	https://www.kcl.ac.uk/research/morecare https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/ioelc/morecare.pdf								





Title:	Maximising the bene	Maximising the benefits of research: Guidance for integrated care systems							
Author(s):	not listed; NHS	not listed; NHS							
Region/Country	ountry: UK Year of publication: 2023 Areas: 13								
Brief summary/	Abstract/Executive s	summary:							
_	This guidance sets out what good research practice looks like. It supports integrated care systems (ICSs) to maximize the value of their duties around research for the benefit of their population's health and care and, through co-ordination across ICSs, for national and international impact								
Keywords: integrated care system,									
Typology of the retrieved data: Regulation and/or guidelines documents Source: Organizations and/or official bodies' publications				ganizations and/or official bodies' publications					
Access details:	https://www.england.nhs.uk/long-read/maximising-the-benefits-of-research/								

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Dissemination Level – Public 141 Version 0.5





Title:	ATMP roadmap	ATMP roadmap								
Author(s):	not listed	not listed								
Region/Country	:	UK	Year of publication:	2021	Areas:	3, 8				
Brief summary/	Abstract/Executive s	summary:								
A roadmap tool setting out key steps and activities in the end-to-end pathway for ATMP from non-clinical research through to treatment provision and monitoring.										
Keywords: cancer research, ATMP, roadmap, regulatory										
Typology of the	retrieved data:	Project documents: deliverables, products, outcomes, from regional, national or European and international projects  Source: Websites, intranets or bulletins								
Access details:										





Title:	Cancer research UK,	Cancer research UK, together we are beating cancer							
Author(s):	not listed	not listed							
Region/Country	y:	UK	Year of publication:	2022	Areas:	3, 5, 8			
Brief summary/	/Abstract/Executive s	ummary:							
An organization v	An organization website with comprehensive information about cancer research and cancer related clinical trials, cancer research strategy, reports and patient insights.								
Keywords: carcer research, cancer types, clinical trial									
Typology of the	Typology of the retrieved data:  Other  Organizations and/or official bodies' publications								
Access details:	https://www.cancerresearchuk.org/sites/default/files/cancer research uk - our research strategy.pdf								

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Dissemination Level – Public 143 Version 0.5





Childhood cancer inequalities in the WHO European Region Title: "Marilys Corbex, Susanne Carai, Marilys Corbex, Helen Crump, Friederike Erdmann, Paola Friedrich, Anita Kienesberger, Sandra Luna-Fineman, Yuliya Lyamzina, Author(s): Marko Ocokoljic, Carlos, Rodriguez-Galindo, Roberta Ortiz Sequeira, Vitaly Smelov, Salvatore Vaccarella, Lin Yang, Isabel Yordi Aguirre" 3, 8, 14 Year of publication: 2022 **Region/Country:** Areas: **Brief summary/Abstract/Executive summary:** The book highlights persistent health inequalities across and within countries in the WHO European Region, emphasizing the importance of achieving health equity. It specifically addresses childhood cancer disparities, noting varying access to diagnosis, treatment, and outcomes. Inequities; Childhood cancer; Europe; WHO **Keywords:** Organizations and/or official bodies' publications Typology of the retrieved data: Books that report empirical information Source: https://www.who.int/europe/publications/m/item/childhood-cancer-inequalities-in-the-who-european-region-2022-report Access details:

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Dissemination Level – Public 144 Version 0.5