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EVALUATION REPORT OF THE IARC MEDIUM-TERM STRATEGY (MTS) 2021–2025

# Evaluation of the International Agency for Research on Cancer (IARC) Medium-Term Strategy (MTS) 2021–2025

# Draft report

# **Contributors and acknowledgements**

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# **Executive Summary**

The International Agency for Research on Cancer (IARC) Medium-Term Strategy (MTS) 2021–2025, endorsed by the Governing Council (GC) in May 2021, outlines the Agency's vision to reduce the global cancer burden. It focuses on four fundamental Pillars – Data for Action, Understanding the Causes, From Understanding to Prevention, and Knowledge Mobilization – alongside three emerging priorities: Evolving Cancer Risk Factors, Implementation Research, and Economic and Societal Impacts of Cancer.

The GC requested an evaluation to assess the implementation of the MTS 2021–2025, according to the MTS evaluation framework and its key performance indicators (KPIs), as endorsed by the GC in May 2022. Conducted in compliance with the WHO evaluation policy and using the UN results-based management methodology, the evaluation used the IOOI model (Inputs, Outputs, Outcomes, Impacts) and included document reviews, bibliometric analyses, interviews, workshops, and case studies.

The MTS evaluation was coordinated by a dedicated MTS Evaluation Working Group with IARC Secretariat and members of IARC governance, supported by the WHO Evaluation Office and external consultants. This evaluation systematically examines the relevance, effectiveness, and impacts of IARC's activities, providing evidence to inform decision-making and guide the development of the next MTS for 2026–2030.

# **Key findings**



The implementation of the MTS 2021–2025 through its four fundamental priorities effectively aligns with the value chain of cancer research and prevention. This strategic framework reflects the structure of IARC's four scientific Pillars, which integrate the Agency's expertise across its Branches. During the MTS period, IARC efficiently allocated human, financial, technological, and informational resources, despite overall underfunding, particularly in key programmes within Pillars I and IV.

#### Research excellence

- → The Agency has maintained high research productivity, publishing an average of 420 publications per year, of which 80% are peer-reviewed articles.
- → IARC's citations-per-publication ratio is 2-6-fold higher than many other leading institutions in oncology, underscoring the high impact and relevance of its research.

#### International collaboration

- → IARC has strengthened global partnerships, collaborating with partners in more than 120 countries.
- → IARC flagship programmes such as GICR, CanScreen5, and the IARC Summer School have largely contributed to capacity building in lowand-middle-income countries (LMICs).

#### **Global cancer control**

IARC has made substantial **contributions to global cancer control** through:

- Groundbreaking scientific studies on the causes of cancer and implementation research that informs prevention policies with evidencebased data.
- → Significant insights into social inequalities and the economic burden of cancer, although establishing a dedicated health economics team remains a pressing need to fully address these challenges.
- Reinforced collaboration with WHO headquarters, with a shared governance structure and strategic workplan, including coordinated efforts on the WHO global cancer initiatives.

#### **Fundamental Priorities**

- → Data for action: IARC successfully advanced its flagship programmes, including GLOBOCAN 2022 and Cancer Incidence in Five Continents (CI5), disseminated through the Global Cancer Observatory. The GICR has improved cancer data collection and quality worldwide, creating a strong foundation for evidence-based action. These efforts were recognized as a core part of IARC's mission.
- → Understanding the causes: IARC's Genomic Epidemiology (GEM) and Nutrition and Metabolism (NME) Branches led high-impact research on cancer etiology and underlying mechanisms using key resources such as the Biobank, the EPIC cohort, and the Mutographs consortium, fostering international partnerships and producing a significant volume of publications in leading scientific journals.
- → From understanding to prevention: IARC made key contributions to cancer prevention through research on primary prevention, screening, and early diagnosis, as exemplified by the CanScreen5 programme. EPR's work on single-dose HPV vaccination demonstrated a public health impact, particularly in LMICs. The ENV Branch showcased leadership in impactful research and policy initiatives, such as the Codes Against Cancer and their regional adaptations.
- Nowledge mobilization: The Learning and Capacity-Building (LCB) Branch supported capacity-building through learning events, including the IARC Summer School, and allowing IARC to host an average of 130 Early Career and Visiting Scientists (ECVS) annually. The Evidence Synthesis and Classification (ESC) Branch delivers globally authoritative evidence through its IARC flagship programmes (Monographs, Handbooks, Classification of Tumours), which are recognized for their scientific quality and policy impact. Actions have been initiated (Overton database) and should be pursued to document these impacts in public health policies.

#### **Emerging Priorities**

- → Evolving cancer risk factors and populations in transition: IARC's multidisciplinary approach enables studies of multidimensional exposures to cancer risk factors. Research Teams led by the NME Branch are key contributors to this priority.
- → Implementation research: The Research for Implementation (RFI) Team was launched in 2024 under EPR impetus, to bridge the gap between scientific evidence and public health decision—making, ensuring that cancer prevention interventions are evidence-based and effective.
- → Economic and societal Impacts of cancer: The Cancer Inequalities Team (CIN) focuses on measuring and addressing social inequalities in cancer, providing a valuable vision at a European scale. Despite some attempts, a dedicated Research Team for health economics and cancer was not established during the MTS period.

#### **Cross-cutting collaborations**

- → Research Teams: Introduced during the MTS 2021–2025, IARC Research Teams have effectively facilitated scientific collaboration across Branches, reducing siloed approaches and enhancing synergy on closely related research topics. This model has strengthened partnerships, improved the visibility of IARC's research, and nurtured the next generation of scientific leaders, demonstrating its value in fostering cross-Branch collaboration and innovation.
- → Research infrastructure: IARC's move to its new headquarters in Lyon Gerland has been a major success of the MTS, offering an attractive work environment with state-of-the-art laboratories and upgraded IT infrastructure. The Biobank and the Scientific IT platform achieved significant milestones, actively contributing to the implementation of the IARC Open Science vision, and leading the way for all research infrastructure.

# Towards MTS 2026–2030: Strengthening collaborations and impact.

Building on the successes and lessons learned from the MTS 2021–2025, IARC is encouraged to center its efforts for the MTS 2026–2030 on:

MTS

2026-2030



# Strategic focus and resource optimization

- > Focus resources on IARC flagship programmes aligned with IARC's unique value in cancer prevention, while enhancing documentation of their impacts on public health policies.
- Consolidate and bring together activities on health economics. modelling, and cancer inequalities.
- → Integrate the WHO Fourteenth General Programme of Work priorities, focusing on climate change's impact on cancer control, and promote a One Health approach to address environmental and population health synergies.
- → Recognize implementation research as a priority.
- → Expand resources for capacity-building programmes to amplify their global impact on cancer control.



# **Coordination with key partners, including WHO**

- Structure IARC's regional training and capacitybuilding initiatives through its local hubs.
- Expand the joint strategic workplan with WHO headquarters to include WHO regional offices.
- > Explore and leverage potential synergies with the WHO Academy to enhance training programmes.



# **Organizational synergies**

- → Implement a matrix organization to foster inter-Branch and cross-Pillar collaborations.
- → Reinforce the Research Teams model and align it with IARC's strategic priorities.
- → Consider expanding Cancer-Focused Teams, ensuring inclusion of initiatives that address the diverse cancer burdens globally.
- → Realign mechanisms of carcinogenesis programmes for stronger synergies and alignment with the MTS 2026-2030 priorities.



#### **Research infrastructure**

- Promote the Global Cancer Observatory (GCO) as the global digital infrastructure on cancer data and a showcase of IARC programmes.
- → Develop a unified strategy for **shared research** platforms based on IARC's Open Science vision.
- → Implement International Organization for Standardization (ISO) standards.



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# List of abbreviations

ABC-DO: African Breast Cancer Disparities in Outcomes

**ASO:** Administrative Services Office

**BDI:** Biostatistics and Data Integration Team

**BFO:** Budget and Finance Office

**BMGF**: Bill & Melinda Gates Foundation

C3B: Computational Biology, Bioinformatics, and Biostatistics Committee CCARE: Childhood Cancer Awareness and Research Evidence Team

**CCEI:** Cervical Cancer Elimination Initiative **CCG:** Computational Cancer Genomics Team

**CIN:** Cancer Inequalities Team **COM:** Communications Team

**CRAs**: Collaborative Research Agreements

CRUK: Cancer Research UK
CSU: Cancer Surveillance Branch

**DAF:** Director of Administration and Finance

DAFO: Office of the Director of Administration and Finance

**DEI:** diversity, equity, and inclusion

**DIR: IARC Director** 

DIR Office: Office of the IARC Director

**EB**: Extrabudgetary Funds **EC**: European Commission

ECA: Oesophageal Cancer Team

ECAC: European Code Against Cancer EDAG: Equity and Diversity Advisory Group EGM: Epigenomics and Mechanisms Branch

ENV: Environment and Lifestyle Epidemiology Branch

**EPIC**: European Prospective Investigation into Cancer and Nutrition

**EPR:** Early Detection, Prevention, and Infections Branch **ESC:** Evidence Synthesis and Classification Branch

FENSA: Framework of Engagement with Non-State Actors

**GBCI**: Global Breast Cancer Initiative

GC: Governing Council

GCO: Global Cancer Observatory

GCSF: Governing Council Special Fund

**GEM:** Genomic Epidemiology

GICC: Global Initiative for Childhood Cancer

GICR: Global Initiative for Cancer Registry Development

HICs: high-income countries

HorM: Hormones and Metabolism Team

**HPV:** human papillomavirus **HRO:** Human Resources Office

IAEA: International Atomic Energy Agency

IARC: International Agency for Research on Cancer

IBB: IARC Biobank

IEC: IARC Ethics Committee

IGOs: intergovernmental organizations IHB: IARC Handbooks programme

**IMO:** *IARC Monographs* programme **ITS:** Information Technology Services

KPI: Key Performance Indicator

LAC: Latin America and the Caribbean

LCB: Learning and Capacity-Building Branch

**LEI:** Lifestyle Exposure and Interventions Team **LMICs:** low- and middle-income countries

LSB: Laboratory Support, Biobanking, and Services LTS: Long-Term Surveillance IARC-Japan Team

MoA: Memorandum of Agreement MoU: Memorandum of Understanding

MTS: Medium-Term Strategy NCDs: noncommunicable diseases

NCI: United States National Cancer Institute NCM: Nutrition, Cancer, and Multimorbidity Team

NGOs: nongovernmental organizations

NIH: United States National Institutes of Health

NME: Nutrition and Metabolism Branch

OCE: Occupational Cancer Epidemiology Team

**OCT**: Oral Cancer Team

**OMB:** Onco-Metabolomics Team **PAF:** population attributable fraction

PBCRs: population-based cancer registries PHDS: Public Health Decision Science Team PLW: Publishing, Library, and Web Services

PS: Participating States RB: Regular Budget

**RCR**: Relative Citation Ratio

**RED:** Risk Assessment and Early Detection Team **RMO:** Resource Mobilization and Management Office

SC: Scientific Council

**SSR:** Services to Science and Research Branch **UICC:** Union for International Cancer Control

**UN:** United Nations

**UNDP:** United Nations Development Programme **UNEP:** United Nations Environment Programme

**UNFPA:** United Nations Population Fund

UNSCEAR: United Nations Scientific Committee on the Effects of Atomic Radiation

VC: voluntary contributions

WCAC: World Code Against Cancer WCRF: World Cancer Research Fund

WCT: WHO Classification of Tumours programme

WHO: World Health Organization

#### Introduction



We must be able to measure progress to make progress. (...) Reliable data is the best way to coordinate response efforts and improve health in all areas.



WHO Director-General Dr Tedros Adhanom Ghebreyesus

#### Ambition of the MTS 2021–2025

In May 2021, the IARC Governing Council (GC) adopted the Medium-Term Strategy (MTS) for 2021–2025 (Resolution GC/63/R4). The vision of the MTS 2021–2025 is to contribute to a world where fewer people develop cancer, which means that IARC will enhance the global understanding of causes of cancer and identify potential prevention measures. This MTS provides guidance on IARC's priorities over 5 years, with a view to ensuring that the Agency's activities have a significant and sustainable impact on the global burden of cancer and, ultimately, on the life and health of the world's citizens.

The MTS 2021–2025 develops IARC's strategic priorities, focusing on four fundamental priorities for cancer prevention research:

- 1. Data for Action (to describe the occurrence of cancer)
- 2. Understanding the Causes (to identify cancer risk factors)
- 3. From Understanding to Prevention (to effectively implement outcomes of cancer research)
- 4. Knowledge Mobilization (to share knowledge about cancer).

IARC is also investing in three emerging priorities: Evolving Cancer Risk Factors and Populations in Transition, Implementation Research, and Economic and Societal Impacts of Cancer.

The action plan of the MTS 2021–2025 aims to consolidate the position of IARC as the global leader in cancer prevention research, as the global hub for Open Science in cancer prevention, and as a recognized United Nations (UN) agency for capacity-building and public health impact. This MTS 2021–2025 translates into the IARC Project Tree, which organizes the activities of the Agency according to projects and the related budget, to ensure proper management of the project portfolio. The four fundamental research priorities are represented by the four scientific Pillars of IARC's organigram.

#### **Request for the MTS evaluation**

In May 2021, the GC requested the IARC Secretariat to define a conceptual framework to assess progress in the implementation of the MTS 2021–2025 (Resolution GC/63/R4). This work required defining methodologies to measure the implementation of the MTS 2021–2025 and providing a framework of indicators to assess the Agency's progress in attaining the strategic objectives as defined in the MTS 2021–2025.

Consequently, a Working Group coordinated by the IARC Secretariat (Véronique Chajès, DIR Office) with the support of a consultant (Olivier Exertier), the Governing Council (Yui Sekitani, Japan), the Scientific Council (SC) (Luis Felipe Ribeiro Pinto, Brazil and Mathilde Touvier, France), and the WHO Evaluation Office (Robert J. McCouch) developed a document "Recommendations of the Working Group on the Evaluation Framework of the IARC Medium-Term Strategy (MTS) 2021–2025 and its Key Performance Indicators (KPIs)". This document outlines the proposed approach and defines the MTS evaluation framework and the proposed KPIs that will enable the monitoring and evaluation of the implementation of the MTS 2021–2025. In the document, KPIs

are complemented by case studies to provide additional qualitative information about the implementation of the MTS 2021–2025.

In May 2022, the GC approved the proposed evaluation approach described in Document GC/64/13 "Recommendations of the Working Group on the Evaluation Framework of the IARC Medium-Term Strategy (MTS) 2021–2025 and its Key Performance Indicators (KPIs)", through the adoption of Resolution GC/64/R12.

#### **Objectives of the MTS evaluation**

In accordance with the request of the GC, the IARC Secretariat prepared the current report on progress in the implementation of the MTS 2021–2025, including quantitative data on the KPIs of the implementation of the MTS and a series of case studies illustrating the main achievements for each of the MTS priorities.

This evaluation of the MTS constitutes the systematic and objective assessment of IARC's strategic programme for 2021–2025: its design, implementation, and results. The aim of this evaluation is to determine the relevance and the fulfilment of the objectives, as well as the development efficiency, effectiveness, and impacts of IARC's activities.

This global evaluation of the implementation of the MTS is complementary to the scientific evaluations of individual Branches, which take place every 5 years through a peer-review process. This evaluation of the MTS provides reliable and useful information, which will serve as a basis for IARC to adapt its decisions and to share lessons for the next MTS.

#### Methodology of the MTS evaluation

The methodology and the content of this evaluation follows the principles of the evaluation framework of the MTS 2021–2025 and its KPIs, as described in the document approved by the Sixty-fourth session of the GC in 2022. The methodology of the MTS evaluation framework relies on the theory of change and the UN results-based management methodology. It is built according to the "IOOI" model to better consider the impact pathway with the causal linkage between Inputs, Outputs, Outcomes, and Impacts.

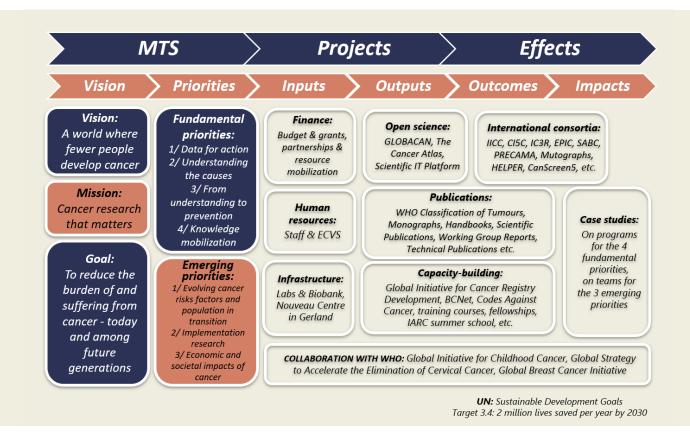
With respect to this evaluation of the MTS 2021–2025, the IARC Secretariat followed this process:

- → Establishment of a Joint SC/GC MTS Working Group (WG) including representation from WHO headquarters (WHO Evaluation Office), through adoption of a resolution at the Sixty-sixth session of the GC in May 2024.
- → Preparation of the evaluation with an evaluability assessment, a bibliometric study, and a document analysis, including: IARC MTS 2021–2025, MTS evaluation framework and KPIs, Report on the evaluability assessment of the MTS, Director's annual reports, Biennial reports, Reports of the Scientific Councils, Scientific reviews of the Branches, Biennial reports on publications, Financial reports, IARC programme and budgets, External Engagement and Resource Mobilization Strategy, Communication Strategy, and any other relevant elements.
- → Internal consultation with all IARC Branches, including interviews with the Branch Heads, the leaders of the Research Teams, etc. Organization of a seminar on the MTS evaluability assessment in 2023 (4 October 2023, with 20 participants), and organization of a two-day seminar with workshops on the MTS evaluation in 2024 (4 and 5 October 2024, with 30 participants). In total, close to 50 interviews were organized for this evaluation.

#### Scope

To ensure that the MTS evaluation framework covers all the dimensions of the IARC MTS 2021–2025, the logic model shown below was developed as part of the definition of the MTS evaluation framework. This logic model summarizes, in a graphic representation, the vision and the priorities for 2021–2025 and the relationships among the resources, activities, outcomes, and impacts of the 5-year programme.

The "impact pathway" developed in the MTS illustrates linkage based on the theory of change, with the causal linkage between Inputs, Outputs, Outcomes, and Impacts. This approach also refers to a conceptual framework for the evaluation of public policy known as the "IOOI" model: Inputs, Outputs, Outcomes, and Impacts. This methodology analyses the programme as a value chain and considers the relationships among its components, to achieve public health impacts.



Logic model of the IARC MTS 2021–2025.

#### **Evaluation questions**

In that context, the overall question of the evaluation of the IARC MTS 2021–2025 is:

→ To what extent has the implementation of the MTS 2021–2025 contributed to generating scientific knowledge for cancer prevention?

Below are the subsidiary questions of the MTS evaluation corresponding to these four dimensions of the IOOI model.



**Inputs:** What are the quantity and quality of the resources invested in the implementation of the MTS? Are they relevant according to IARC's ambitions? Do they align with the goals set forth by IARC?



Outputs: What has been done and produced according to the MTS action plan? Are these outputs aligned with IARC's priorities?

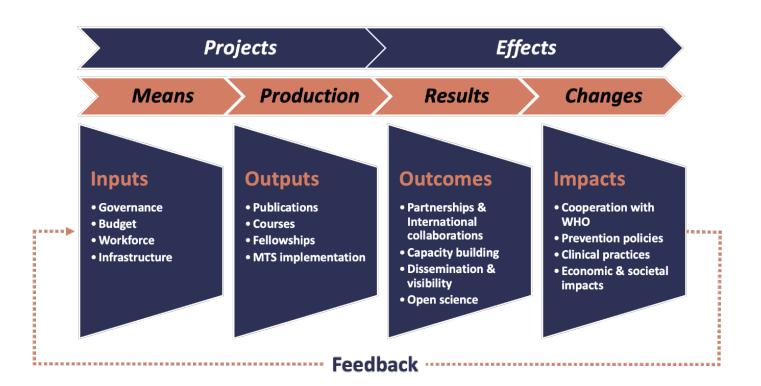


Outcomes: What progress has IARC made towards achieving the objectives of the MTS? What are the results for stakeholders?



Impacts: What are the long-term, sustainable changes in cancer prevention that are attributable to the MTS?

The MTS evaluation framework defined four categories of indicators and KPIs for each of the four dimensions of the framework (Inputs, Outputs, Outcomes, and Impacts), as summarized below. These indicators are detailed in the document approved by the Sixty-fourth session of the GC in 2022, to assess progress in the implementation of the MTS 2021–2025.



#### **Organization of the MTS evaluation**

#### **Working Group**

The evaluation of the IARC MTS is a decentralized evaluation managed by a dedicated team, the MTS Evaluation Working Group, with the methodological support of the WHO Evaluation Office and the contribution of dedicated consultants working with the IARC Secretariat.

The WHO Evaluation Office appointed Anand Sivasankara Kurup to fulfil this role and participate in the MTS Evaluation Working Group. The role of the WHO Evaluation Office is to provide methodological support and quality assurance, to make sure the MTS evaluation is in line with the WHO Evaluation Policy (2018), the WHO Evaluation Practice Handbook (2013), and the UNEG Norms and Standards for Evaluation (2017). Two consultants (Olivier Exertier and Anna Schmütz) were contracted to support the IARC Secretariat in the evaluation of the MTS 2021–2025, following the recommendations of the Working Group and the IARC Senior Advisory Team on Management (SAT).

The evaluation of the MTS 2021–2025 was conducted throughout 2024 by the MTS Evaluation Working Group. The members of this MTS Evaluation Working Group were appointed by the SC and the GC through the adoption of a resolution at the Sixty-sixth session of the GC in May 2024. The Working Group is composed of members of the SC, the GC, WHO headquarters, and the IARC Secretariat, working in close collaboration with the SAT. The members of the MTS Evaluation Working Group are:

- IARC SC: Luis Felipe Ribeiro Pinto (Brazil), Pål Richard Romundstad (Norway),
- IARC GC: Elena María Domenech Cruz (Spain), Thomas Dubois (France),
- WHO headquarters: Anand Sivasankara Kurup (WHO Evaluation Office),
- IARC Secretariat: Véronique Chajès (Director's Office),
- Consultants mandated by IARC: Olivier Exertier and Anna Schmütz.

This MTS Evaluation Working Group prepared this draft report on the evaluation of the MTS 2021–2025, including a series of case studies illustrating the main achievements in each of the MTS priorities, supported by quantitative data on the proposed indicators outlined in the "Evaluation Framework of the IARC MTS 2021–2025".

#### **Timeline**

This evaluation of the MTS 2021–2025 is a 5-year process, corresponding to the entire duration of the implementation of the MTS. In 2021, after the approval of the MTS, the evaluation framework and KPIs were defined, with the support of the Working Group responsible for the report titled "Evaluation Framework of the IARC Medium-Term Strategy (MTS) 2021–2025 and its Key Performance Indicators (KPIs)". This document was submitted for discussion to the SC in February 2022 and for approval to the GC in May 2022.

In 2023, the IARC Director organized a seminar dedicated to the MTS with the SAT, and the IARC Secretariat conducted an evaluability assessment to prepare for the MTS evaluation. The document on the MTS evaluability assessment was submitted for discussion to the SC in February 2024 and for approval to the GC in May 2024.

The document analysis for the preparation of the MTS evaluation in 2024 includes: IARC MTS 2021–2025, MTS evaluation framework and KPIs, Report on the evaluability assessment of the MTS, Director's annual reports, Biennial reports, Reports of the Scientific Councils, Scientific reviews of the Branches, Biennial reports on publications, Financial reports, IARC programme and budgets, External Engagement and Resource Mobilization Strategy, Communication Strategy, and some other documents, mentioned in the appendices.

The evaluation of the MTS was run in 2024, according to the following steps:

- → January-March 2024: Document analysis and interviews with the IARC programme leaders; preparation of the MTS case studies.
- → April 2024: Definition of the terms of reference of the MTS evaluation with the experts of the WHO Evaluation Office.
- → April-June 2024: Interviews with the leaders of the IARC Research Teams to gather the elements required for the MTS evaluation.
- → May 2024: Discussion and approval of the MTS evaluability assessment and definition of the members of the MTS Evaluation Working Group by the GC.
- → July 2024: "Bibliometric analysis for the evaluation of IARC Medium-Term Strategy for 2021–2025" document for consideration by the Working Group.
- → September 2024: Meeting of the MTS Evaluation Working Group, on the methodology and the first contents of the MTS evaluation.
- → October 2024: Seminar and workshops on the MTS evaluation with the IARC management.
- → November 2024: Meeting of the MTS Evaluation Working Group and "Draft of the Evaluation Report" with the contributions of the Working Group members.
- → December 2024: Distribution of the draft MTS Evaluation Report to the members of the SC.

In that context, this draft report on the evaluation of the MTS 2021–2025 will be submitted to the SC in February 2025 for discussion and recommendations and to the GC in May 2025 for discussion and endorsement through the adoption of a Resolution.

The MTS evaluation report is structured around the framework of the MTS evaluation, encompassing Inputs, Outputs, Outcomes, and Impacts, as well as the overall conclusions drawn from the evaluation. The recommendations outlined in this report will serve as a foundation for shaping the upcoming MTS 2026–2030, ensuring continuity and alignment with IARC's strategic objectives.

# 1. MTS Inputs

→ The first category of Key Performance Indicators (KPIs) for evaluating the implementation of the MTS 2021–2025 focuses on inputs. These encompass the human, financial, technological, and informational resources used to achieve the intended outcomes. Within the framework of the IARC's MTS, these inputs specifically pertain to the Agency's governance (1.1), budget (1.2), workforce (1.3), and infrastructure (1.4).





#### 1.1 Governance

#### **Governance inputs**

Main ambitions of the MTS 2021-2025:

Welcome new PS

#### KPIs:

Admission of new PS

Source: Director's Office, SSR

# Evolution and current status of IARC's Participating States

The admission of new Participating States (PS) was defined as the number one indicator in the Evaluation Framework of the IARC MTS 2021–2025. The integration of new PS is the main priority to consolidate the multilateral governance of IARC and to provide long-term resources (statutory contributions) for the Agency to better implement its mission. With the addition of China in May 2021, followed by Saudi Arabia and Egypt in May 2024, IARC now has a total of 29 PS. These PS are categorized into five groups based on the WHO scale of

assessment, as detailed in Table 1. Table 2 shows the evolution of the number of IARC PS since 2010 (with the MTS 2010–2015 as a baseline). Over the past two MTS periods, IARC has averaged the integration of one new PS every 2 years, factoring in the departure of Turkey in 2019. During the current MTS, the Agency has accelerated its attracting efforts, adding three new PS between 2021 and 2024. With all countries from Groups 1, 2, and 3 already part of IARC, future admissions will focus on countries in Groups 4 and 5. Among the 16 countries in Group 4, 9 are already PS.

Table 1. Current list of IARC Participating States <sup>1</sup>										
Groups of countries	Participating States									
Group 1	China, Japan, USA									
Group 2	France, Germany, UK									
Group 3	Australia, Brazil, Canada, Italy, Republic of Korea, Spain									
Group 4	Austria, Belgium, Denmark, India, Netherlands, Norway, Russian Federation, Saudi Arabia, Sweden, Switzerland									
Group 5	Egypt, Finland, Hungary, Islamic Republic of Iran, Ireland, Morocco, Qatar									

Table 2. Growth and distribution of IARC Participating States over time <sup>2</sup>										
MTS periods	Year	Number of PS	Evolution							
MTS 2010-2015	2010	21	-							
	2011	22	+1							
	2012	22	-							
	2013	24	+2							
	2014	24	-							
	2015	25	+1							
MTS 2016-2020	2016	25	-							
	2017	25	-							
	2018	26	+1							
	2019	27	+1							
	2020	26	-1							
MTS 2021-2025	2021	27	+1							
	2022	27	-							
	2023	27	-							
	2024	29	+2							

<sup>&</sup>lt;sup>1</sup> Source: IARC/WHO, DIR Office and SSR, July 2024.

<sup>&</sup>lt;sup>2</sup> Source: IARC/WHO, DIR Office and SSR, July 2024



#### **Activities with current Participating States**

The bibliometric analysis<sup>3</sup> conducted for the evaluation of the MTS 2021–2025 highlights IARC's extensive co-authoring with international scientific partners. Covering the period from 2021 to May 2024, the data reveal that the majority of IARC publications (88%) are co-authored with partners based in PS. Notably, as shown in bold in Table 3, 22 of the top 25 countries for IARC scientific co-authoring are PS.

Table 3. Countries of co-authoring for	· IARC scientific publicati	ons for 2021–May 2024
Countries of scientific partners	Number of co-publications	% of co-publications
1/ UK	684	51.82%
2/ USA	637	48.26%
3/ GERMANY	408	30.91%
4/ ITALY	359	27.20%
5/ SPAIN	341	25.83%
6/ SWEDEN	294	22.27%
7/ NETHERLANDS	293	22.20%
8/ FRANCE	276	20.91%
9/ NORWAY	248	18.79%
10/ AUSTRALIA	243	18.41%
11/ CANADA	237	17.96%
12/ DENMARK	236	17.88%
13/ CHINA	135	10.23%
14/ GREECE	127	9.62%
15/ SWITZERLAND	117	8.86%
16/ BELGIUM	105	7.96%
17/ AUSTRIA	95	7.20%
18/ BRAZIL	95	7.20%
19/ FINLAND	86	6.52%
20/ JAPAN	86	6.52%
21/ COLOMBIA	84	6.36%
22/ INDIA	77	5.83%
23/ ISLAMIC REP. OF IRAN	65	4.92%
24/ IRELAND	60	4.55%
25/ SOUTH AFRICA	60	4.55%

Other PS also rank prominently in IARC's list of co-authoring countries, such as the Russian Federation (32nd), the Republic of Korea (33rd), and Hungary (35th). After Egypt's entry as a PS in May 2024 (ranked 57th in co-authoring), the Secretariat developed a collaboration roadmap with Egypt to strengthen cancer research and initiatives. This roadmap prioritizes key projects on cancer registries, breast cancer, hepatitis surveillance, and bladder cancer, with dedicated focal points assigned for each area. A series of structured meetings has been planned to ensure the successful implementation of this enhanced collaboration.

<sup>&</sup>lt;sup>3</sup> Source: IARC/WHO, PLW, June 2024.



#### Actions to welcome new Participating States

The IARC Secretariat has identified a shortlist of potential countries for PS membership. This list includes Colombia, Czechia, Greece, Indonesia, Kazakhstan, Kuwait, Luxembourg, Malaysia, Mexico, New Zealand, Poland, Portugal, South Africa, and the United Arab Emirates.

Becoming an IARC PS offers countries the opportunity to contribute to advancing global cancer research, with a particular emphasis on low- and middle-income countries (LMICs). In return, potential PS countries seek tangible benefits from their contributions.

The Secretariat has developed a compelling investment case, supported by targeted communication materials, to present to prospective PS. This strategy emphasizes benefits such as internationalizing their research efforts and shaping the global cancer prevention agenda. In addition, the Secretariat tailors its pitches to address the specific priorities and interests of individual countries. For example, understanding Saudi Arabia's ambition to enhance its regional leadership in the Gulf, IARC proposed the establishment of a regional hub in Riyadh for the CanScreen5 programme. This initiative aims to consolidate Saudi Arabia's position as a leading regional centre for cancer research and training. To further support attracting efforts, the Secretariat has cultivated networks of influential advocates. Raising IARC's visibility and appeal in a country often relies on the active support of respected individuals who can facilitate access to key government stakeholders and advocate for membership. This approach played a pivotal role in securing Saudi Arabia as a PS in May 2024, with the crucial support of Dr Samar Jaber Alhomoud, who is a colorectal surgeon and researcher at King Faisal Hospital and the current chairperson of the IARC Ethics Committee. Dr Alhomoud's engagement was instrumental in navigating Saudi Arabia's administrative processes and securing its membership.

Welcoming a PS is a long-term endeavour that requires sustained effort over several years. The success of these efforts is exemplified by China's integration as a PS in 2021. To date, tailored pitches and the strategic use of advocacy networks have contributed to the addition of three new PS under the current MTS. To accelerate the welcome of the 14 top-priority countries, IARC should consider allocating additional resources to this critical objective (see Main conclusions and recommendations: inputs). Enhanced support from senior management could further strengthen these efforts and expedite the process of securing new PS.



# 1.2 Budget

#### **Budget inputs**

Main ambitions of the MTS 2021-2025:

- → Budget increase: 25% in 10 years
- Diversification of resources
- Increase of extrabudgetary funds
- Innovative resource mobilization

#### KPIs:

- Evolution of total and regular budget
- Number and evolution of funders
- Resource mobilization and fundraising (case study)

**Source:** DIR Office, SSR (BFO and RMO)

IARC's budget relies on two sources of revenue: the Regular Budget (RB)funded by the PS and the Extrabudgetary (EB). EB consists of Voluntary Contributions (VC), as well as private individual donations and some additional resources. The tables on VC presented below refer mainly to competitive grants, direct contributions, and donations.

#### Evolution of IARC's regular budget

Table 4 presents the evolution of IARC's Regular Budget (RB) in million euros (€) per year and per biennial budget from 2016 to 2025. Notably, the biennial budget for 2020–2021 spans two distinct MTS periods.

Between the biennial budgets of 2016-2017 and 2024-2025, IARC's RB increased by +12.1% in total, which

equates to an average annual increase of +1.44%. However, this growth has not kept pace with the rising costs of operations:

- The annual salary increase for General Service (GS) and Professional (P) staff averages +2%, exceeding the RB growth rate.
- The inflation rate in France has surged by +17.3% between 2016 and 2023, according to INSEE standards (French National Institute of Statistics and Economic Studies). As a result, IARC has experienced a 9.7% loss in purchasing power during this period, highlighting the challenge of maintaining financial sustainability amidst rising costs.

	Table 4. Evolution of IARC's regular budget in million € since 2016⁴														
Biennial	2016-	-2017	2018	-2019	2020	-2021	2022-	-2023	2024–2025						
RB in million €			€44.15		€44.15		€4	5.37	€48.68						
Year	2016 2017		2016 2017 2018 20		2020	2021	2022	2023	2024	2025					
RB in million €	€21.36	€22.06	€21.91	€22.24	€21.87	€22.28	€22.41	€22.96	€24.32	€24.36					

#### Evolution of IARC's grants and contracts

Table 5 illustrates the evolution of IARC's VC, including grants and contracts, from 2016 to 2023. These funds primarily come from competitive grants, regardless of whether IARC coordinates the programmes. The amount of VC has doubled, rising from €10 million in 2016 to €20 million in 2023. Notably, 2022 marked an exceptional year, with €24.38 million secured through grants and direct funding. During the current MTS period (2021–2023), the annual average amount of VC signed (€21.28 million) is approaching parity with the average RB (€22.55 million). However, it is important to note that these figures cannot be directly compared due to differences in budgetary timeframes. For context, during the previous MTS period (2016–2020), annual VC contributions

<sup>4</sup> Source: IARC/WHO, SSR (BFO), May 2024.



amounted to only half of the RB (€11 million per year), highlighting the significant growth in external funding over time.

Т	Table 5. Evolution of IARC's grants and contracts in million € since 2016 <sup>5</sup>												
Year	Number of applications	Number of signed contracts	Total value of signed contracts (million €)	Value attributed to IARC (million €)									
2016	183	65	€28.31	€10.24									
2017	193	65	€38.93	€11.86									
2018	204	68	€20.99	€9.18									
2019	236	81	€41.49	€12.41									
2020	236	94	€20.07	€12.34									
2021	245	101	€36.18	€19.04									
2022	203	123	€70.34	€24.38									
2023	207	109	€72.87	€20.42									

From 2021 to 2023, IARC signed contracts with a relatively stable number of funders: 63 in 2021 (for €19.03 million), 62 in 2022 (for €24.38 million), and 68 in 2023 (for €20.42 million). The number of funders has remained consistent over the years and does not significantly influence the overall volume of grants.

As shown in Table 6, the distribution of VC highlights a concentration of funding among a small group of key funders. The top three funders – the United States National Cancer Institute, the Bill & Melinda Gates Foundation, and the European Commission – account for 55% of the total VC secured in 2021–2023. The top 7 funders represent 77% of VC, and the top 10 funders collectively contribute 84% of the total VC. Most of IARC's primary funders are based in the USA and European countries (e.g. the European Union, France, UK, and the Netherlands), with the notable exception of the Gulf Center for Disease Prevention and Control (Gulf CDC) in Saudi Arabia.

Ta	ble 6. Top 10 funders of IARC's f	or VC in 2021-2023
Rank	Funders	Total IARC budget in €
1	NIH-NCI (USA)	€12 182 728
2	BMGF (USA)	€11 973 448
3	EC (EU)	€10 950 951
4	INCa (FR)	€7 408 727
5	WCRF (UK)	€2 801 672
6	NL-MoH (NL)	€1998055
7	MRC (UK)	€1 941 921
8	CRUK (UK)	€1778962
9	WHO (headquarters and regions)	€1 570 611
10	Gulf CDC (SA)	€1 046 601

<sup>5</sup> Source: IARC/WHO, SSR (RMO), May 2024.



# Resource mobilization and fundraising Case study

#### **Structure**

#### Governance framework

The IARC resource mobilization and fundraising strategy was defined with the IARC governance of IARC, with a presentation at the GC62 in May 2020. Each year, the GC is requested to approve the grants and contracts (above €100 000 per year), as well as the donations for IARC; all that information is publicly available online on the IARC website and links below.

#### **Summary**

As part of the preparation of the MTS 2021–2025, IARC defined in 2020 a funding strategy with projections for resource mobilization for the next 10 years (2020–2029), corresponding to 5 biennial budgets. Those operational plans for the resource mobilization strategy highlight four priorities:

- → Increase assessed contributions through the admission of new PS;
- Enlarge direct and flexible funding through expanding strategic engagement with state and non-state actors;
- Widen and strengthen competitive grants by proactively identifying funding opportunities and coordinated submission of high-quality grant applications;
- Explore innovative resource mobilization and fund-raising campaigns, some of them targeting private individuals and private companies.

Based on those plans and projections, the IARC Secretariat set an ambitious target of a 25% increase of its budget over the next 10 years, which corresponds to IARC mobilizing €418 million from 2020 to 2029. This strategy was presented to the IARC Governing Council of IARC in May 2020 (GC62).

Some specific groups or committees with the members of IARC governance also directly contribute to the definition and to the implementation of this resource mobilization and fundraising strategy, especially:

- The subcommittee on the admission of new Participating States,
- The financing dialogues between IARC and GC Representatives,
- The Working Group on Sustainable Financing for the IARC.

#### Resources

The resource mobilization and fundraising strategy is managed mainly by two entities within IARC:

- → The Resource Mobilization and Management (RMO) team in the Budget and Finance Office (SSR), which supports the Agency's resource mobilization activities through the identification of funding opportunities and the support for grant preparation, performs due diligence on potential donors and partners in line with FENSA, and supports implementation of active grants, for instance regarding donor reporting and payments.
- → The Director's Office, which is responsible for strengthening and expanding strategic engagements with its network of collaborators, with governmental and nongovernmental partners, with funding agencies, with high-net-worth individuals, with WHO headquarters and WHO regional offices, and with current and potential new IARC PS.



#### **Links with WHO**

The collaboration of IARC with WHO regarding its resource mobilization and fundraising plan concerns mainly the implementation of the Framework of Engagement with Non-State Actors (FENSA), including some discussions with WHO headquarters about complex cases. According to FENSA, non-state actors are nongovernmental organizations, private sector entities, philanthropic foundations, and academic institutions. WHO engages with non-state actors in view of their significant role in global health for the advancement and promotion of public to use their own activities to protect and promote public health.

In that context, FENSA aims to strengthen the WHO engagement with non-state actors for the benefit and interest of global public health, thanks to "a robust framework that enables engagement and serves also as an instrument to identify the risks, balancing them against the expected benefits, while protecting and preserving WHO's integrity, reputation and public health mandate". For each of the four groups of entities mentioned above, IARC determines through due diligence whether the collaboration with these non-state actors is appropriate. This due diligences and risk assessment are implemented not only for IARC projects but also for all grant applications.

# **Global reach and impact**

As specified above, the annual average amount of VC (€21.28 million in grants) is becoming similar to the average RB (€22.55 million). In 2023, for instance, the IARC's expenditure rate was 56% on RB and 44% on VC.

This evolution means that during the current MTS period IARC is witnessing a change in its funding model. This increase of VC with respect to a rather static RB raises several questions for IARC.

This increase of VC with respect to a rather static RB raises several questions for IARC:

- First, the funders' priorities may affect the IARC scientific applications and programmes. Considering that very few calls for applications are dedicated to LMICs, it is a real concern regarding IARC's mission, which includes "conducting research in low- and middle-income countries through partnerships and collaborations with researchers in these regions".
- This new RB/EB ratio generates additional costs for IARC, related to grant applications, grant management, grant implementation, and self-financing portion. IARC has to comply with donor-specific implementation and reporting requirements, which differ from grant to grant. This includes the implementation of specific reporting tools (such as time sheets) for each of the funders. In addition, many funders do not permit the charging of overhead, which means grant management costs must be

borne by the RB or by other funders who do pay overhead.

→ Finally, the increasing number of grants also means dealing with increased administrative work, including for example, a higher number and frequency of recruitments, especially of ECVSs and short-term staff.

A total investment of US\$ 24.5 billion was evaluated regarding the global funding for cancer research in 2016–2020 (public and philanthropic investments), including US\$ 19.8 billion for cancer treatment (pre-clinical research and Phase 1–4 trials). The annual amount of global cancer funding is close to US\$ 5 billion. This means that IARC represents nearly 1% of this global funding for cancer research and 10% of public health research in oncology. As shown in the table below, the major funders in 2016–2020 were the USA, UK, European Union, China, and Japan, followed by Australia and the UK.



	Number of awards (n=66388)	Funding (\$US 24 451 417 116)	Median funding (\$US)	Mean funding (\$US)
Australia	1073 (1.6%)	717764311 (2.9%)	439 547 (250 323 - 608 889)	674590 (2304325)
Canada	4086 (6.2%)	686 040 249 (2-8%)	80750 (23 409–152 344)	174831 (447828)
China	15 168 (22-8%)	1077214855 (4.4%)	58 086 (30 768 - 87 689)	71018 (121584)
European Commission	835 (1.3%)	1323023904(5:4%)	239 093 (185 072-2 361 314)	1590173 (2338774)
Germany	1209 (1.8%)	209 654 656 (0-9%)	115 401 (103 275-157 527)	178733 (377847)
Japan	12493 (18-8%)	1006071774(4·1%)	39 872 (37728-43 968)	81331 (305378)
UK	2511 (3-8%)	2393188623(9.8%)	203 445 (134 194-419 157)	494032 (1654973)
USA	16503 (24.9%)	14016 920 819 (57-3%)	432 619 (189 338-1 004 250)	849355 (1565062)
Other	12510 (18-8%)	3021538399 (12-4%)	116 431 (42 834-317 132)	249 178 (583 226)

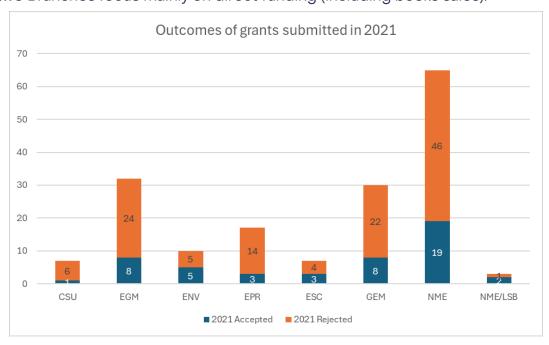
Global funding for cancer research between 2016 and 2020.6

#### Interface with other Pillars and Branches

The Director's Office and the RMO team work with all the IARC scientific Branches of IARC, for grant applications as well as on the coordination for the collaborations with non-state actors and IARC PS.

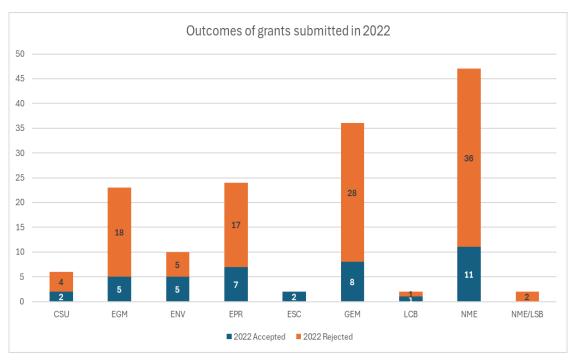
# **Key Performance Indicators (KPIs)**

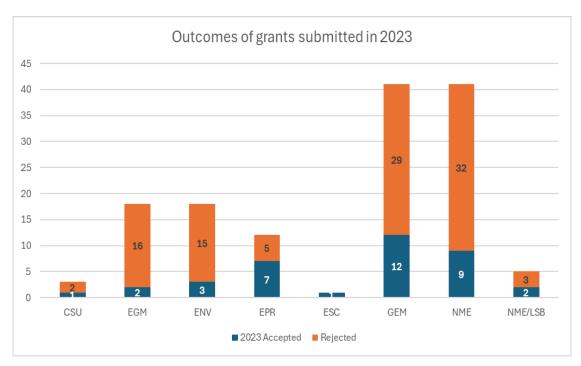
→ Number and outcomes of grant applications: The following tables illustrate the numbers and outcomes of IARC grant applications in 2021, 2022 and 2023, for each IARC scientific Branch of IARC. The 2 Branches in Pillar 2 (GEM and NME) produce the highest volume of grants applications every year. The Branches in Pillar 1 (CSU) and Pillar 4 (ESC) provide a limited number of grant applications, because their activities are not adapted for scientific calls and those two Branches focus mainly on direct funding (including books sales).



<sup>6</sup> Source: Global funding for cancer research between 2016 and 2020: a content analysis of public and philanthropic investments, The Lancet Oncology, Volume 24, Issue 6, 2023







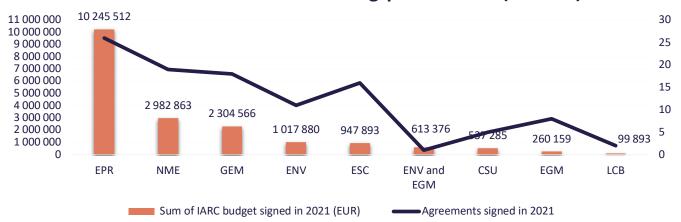
→ Distribution of grants and voluntary contributions per Branch: The tables below<sup>7</sup> present a summary of the distribution of grants and voluntary contributions per Branch. The following annual charts also include the total amount of grants signed in euros, as well as the number of agreements. Over the 3 first years of the MTS (2021–2023), IARC has raised €63,83 million in grants, corresponding to an average of more than €21 million per year. EPR is the most successful Branch, with nearly €23 million in grants signed in 3 years, followed by NME (€11.6 million), GEM (€8.5 million) and ENV (€8.0 million).

<sup>7</sup> Source: IARC/WHO, SSR (RMO), July 2024

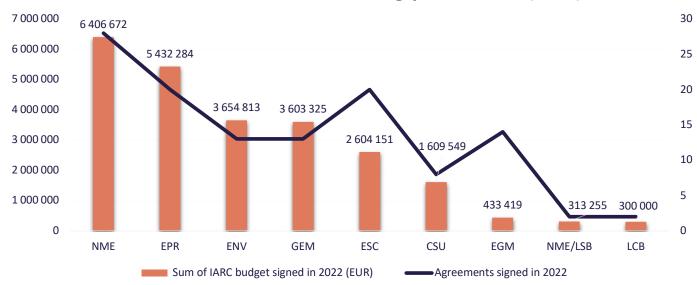


	Signed grants of IARC in € for 2021-2023									
Branches	2021			2022		2023	TOTAL			
EPR	€	10,245,512	€	5,432,284	€	7,214,221	€	22,892,017		
NME	€	2,982,863	€	6,406,672	€	2,161,179	€	11,550,714		
NME/LSB			€	313,255	€	160,722	€	473,977		
GEM	€	2,304,566	€	3,603,325	€	2,634,881	€	8,542,772		
ENV	€	1,017,880	€	3,654,813	€	3,290,619	€	7,963,312		
ESC	€	947,893	€	2,604,151	€	1,610,806	€	5,162,850		
CSU	€	537,285	€	1,609,549	€	1,249,368	€	3,396,202		
EGM	€	260,159	€	433,419	€	387,501	€	1,081,079		
LCB	€	99,893	€	300,000	€	450,907	€	850,800		
ENV/EGM	€	613,376					€	613,376		
EGM/GEM					€	216,960	€	216,960		
CSU/EPR					€	531,655	€	531,655		
Cross cutting	€	28,000	€	21,231	€	507,700	€	556,931		
Grand Total	€	19,037,427	€	24,378,699	€	20,416,518	€	63,832,644		

#### 2021 distribution of funding per branch (in EUR)

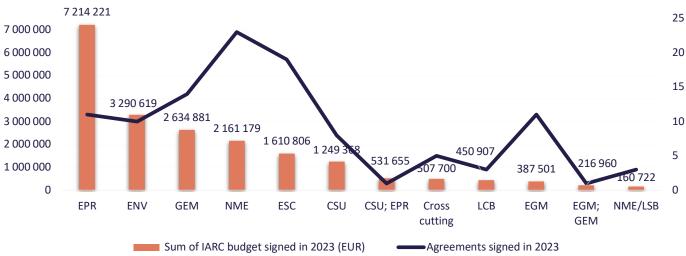


## 2022 distribution of funding per branch (EUR)

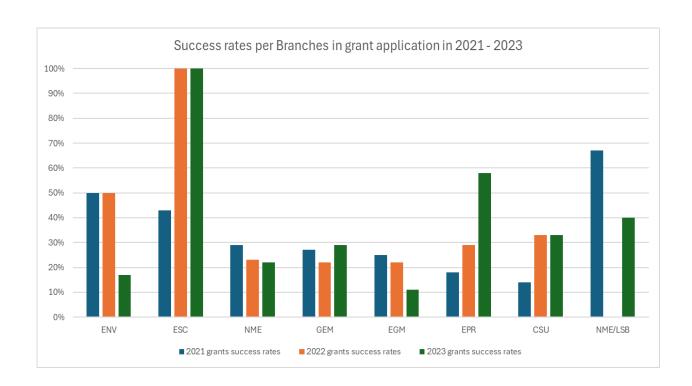








→ Success rates of IARC's grant applications: The table below<sup>8</sup> shows the success rates per Branches for grant applications during the 2021–2023 period. The average success rates of IARC scientific Branches are on average between 30%–40%, although there are significant disparities. It is important to note that the base is not the same from one Branch to another. ESC has a 100% success rate because it was awarded 3 grants out of 3 applications during these years. The benchmarks provided by RMO on the success rates per calls for the key funders of the Agency demonstrate IARC's high performance for grant applications compared with the average success rates for NIH, European Commission, and INCa calls.



<sup>8</sup> Source: IARC/WHO, SSR (RMO), July 2024



	Success rates on grant applications in 2021–2023													
Years	Years Average % of success rate for NIH Average % of success rate for European Average % of success rate for III Calls Commission Calls													
	IARC applications	All applications	IARC applications	All applications	IARC applications	All applications								
2021	25%	14%	43%	16%	39%	21%								
2022	17%	15%	27%	16%	29%	-								
2023														

→ Indirect costs for grants: The chart below details the indirect cost agreed with the funders for the IARC active grants in June 2024. Most of these grants have 13% indirect costs, corresponding to the IARC standard. Indeed, IARC has defined 13% as the standard minimum indirect cost rate, but in practise the Agency does not manage to collect that target. Only some European grants provide higher indirect costs (25%). 14 funders do not allow any indirect costs, and 10 other funders offer a rate below the 13% standard. As a result, the indirect cost rates are not sufficient to cover IARC's administrative costs.

#### IARC active grants 2024 - IDC agreed per funder





# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

As shown in the chart below<sup>9</sup>, the IARC resource mobilization strategy of IARC relies on four strategic priorities:

- → Increase assessed contributions through the admission of new PS.
- → Enlarge direct and flexible funding through expanding strategic engagement with State and NSAs.
- → Widen and strengthen competitive grants by proactively identifying funding opportunities and coordinated submission of high-quality grant applications.
- → Explore innovative resource mobilization and fund-raising campaigns, some of them targeting private individuals and private companies.

#### Achievements of assigned objectives

During the period 2021-2024, IARC has some made important progress on each of the 4 objectives of the resource mobilization strategy:

New Participating States: With the official integration of China in 2021, as well as Egypt and Saudi Arabia in 2024, IARC is in line with the objectives of new Participating States (1 new PS per biennial budget). Therefore, the Regular Budget (RB) of IARC will mechanically increase, thanks to the admission of one additional group 1 country (China; €1.72 million of assessed contributions per year), one additional group 4 country (Saudi Arabia; €0.75 million of assessed contributions per year), and one additional group 5 country (Egypt; €0.62 million of assessed contributions per year). After the integration phase, those 3 new PS will represent more than €3 million of additional assessed contributions per year for IARC. This evolution is extremely positive. However, to reach

# Integration into the IARC Project Tree

The IARC resource mobilization and fundraising strategy directly contributes to:

- → The Level 2 Objective #5, "Strengthening the Agency's leadership, governance, strategic engagement, and advocacy" and more specifically
- → The Level 3 Objective: Objective 5.3: "Create and maintain key strategic engagement with stakeholders at national, regional, and international organizations, and scale up resource mobilization activities".

the objective of the Resource Mobilization Strategy (an increase of 10% in assessed contributions by 2029), IARC needs to speed up the admission of new PS or negotiate a higher level of assessed contributions.

- → Direct funding: During the current MTS, IARC is obtaining significant resources thanks to direct funding, including from US CDC, BMGF, and Medical Research Council UK in 2022, as well as from Ministry of Health of Netherlands, BMGF, and Gulf CDC. These new resources are significant and are in line with the objective of the Resource Mobilization Strategy (€3 million per year).
- → Grant applications: As detailed above, IARC has been very successful in increasing its funding from grants. The amount of VC to IARC has doubled, from €10 million in 2016 to €20 million in 2023. In 2022 there was an exceptional performance, with €24.38 million in grants. During the current MTS period (2021–2023), the annual average amount of VC signed (€21.28 million in grants) is becoming similar to the average RB (€22.55 million). Considering this performance, IARC may already reach, in advance, the objective of the Resource Mobilization Strategy

 $<sup>9 \ \</sup>mathsf{Source}; \mathsf{IARC}, \mathsf{OPERATIONAL} \ \mathsf{PLANS} \ \mathsf{FOR} \ \mathsf{THE} \ \mathsf{RESOURCE} \ \mathsf{MOBILIZATION} \ \mathsf{STRATEGY}, \mathsf{May} \ \mathsf{2020}$ 



defined for 2029 (€110 million). The results-based budgeting (RBB) approach that IARC is using for its biennial budget 2026–2027 may also contribute to this ambition.

→ Fund-raising campaigns: As part of the Nouveau Centre project, IARC has run a very active fundraising campaign generating more than €2 million of financial and in-kind donations. This fundraising campaign includes contributions from high-net-worth individuals as well as a large number of individuals thanks to the crowdfunding platform created for the occasion and the online platform. Donations represent €295 000 in 2021, €24 000 in 2022, and €20 000 in 2023. IARC is working on a legacy programme to reach higher amounts. Some additional initiatives are required to match the very ambitious target of the Resource Mobilization Strategy defined in 2020 (€32 million in 2029).

# Main challenges and future perspectives

#### Challenges

- As mentioned above, IARC's top 7 funders represent more than three quarters (77%) of total IARC voluntary contributions, and all of these external funders of IARC are located in HICs: the USA and European countries (European Union, France, UK, and the Netherlands).
- This concentration of external funds generates more efficiency for IARC; the learning curve allows the Agency to better address the requirements and expectations of the major funders. However, it may also expose IARC to potential risks and constraints. It leads to a higher dependency on the funder priorities and financial exposure in case of loss of a major funder, such as NCI, BMGF, or EC.
- The IARC management considers that one IARC flagship programme, the IARC Monographs
  on the Identification of Carcinogenic Hazards to Humans, is potentially at risk, because 59% of
  its funding comes from two external funders: the National Institutes of Health National Cancer
  Institute (NIH NCI) and the National Institute of Environmental Health Sciences (NIEHS), in the
  USA.
- It is also worth considering this top list in the light of global funding for cancer research in 2016–2020. The figures below on the global funding of cancer research confirm the interest for IARC to work more closely with national agencies in Australia, Canada, Germany, and Japan, but also invite IARC to consider China in the priority list. To improve its collaborations with these top funders and its resource mobilization, IARC should consider defining and implementing key account management (KAM). KAM consists of planning and managing a mutually beneficial partnership between an organization and its most important partners. To some extent, IARC has initiated such an approach with the European Commission, including the recruitment of a Project Management Officer (PMO) position with significant experience with EC grants.

#### **Perspectives**

In 2024, IARC is experimenting with a results-based budgeting approach for the definition of its biennial budget 2026–2027:

→ In line with the UN guidelines, results-based budgeting (RBB) is a budgeting approach that aligns financial resources with the strategic priorities of the organization. It implies resource allocation based on the expected results or outcomes of the scientific programmes, rather than simply allocating funds based on the historical spending of the Agency.



- → For IARC, this new RBB approach aims to better align the next budget with the MTS ambitions, thanks to three level of priorities for the scientific programmes, including the 10 IARC flagship programmes. This new RBB approach also aims to assess the total cost of IARC's programmes
  - (through Programme and Project Proposals), including their funded and unfunded components, with resources linked to specific, agreed-upon results and impacts.
- → This RBB approach should also provide a comprehensive vision of IARC's budget, integrating Regular Budget and Extrabudgetary plans, which better corresponds to the reality of IARC's activities. Another objective is to identify more clearly the funding gaps to allow strategic discussions and decisions with the governance of IARC. It should also help with prioritizing the targets for resource mobilization. Finally, this new budget approach should facilitate the implementation of staff positions funded on both RB and EB, to avoid a system with two categories of personnel, which causes some managerial challenges.

#### For more details

- → Operational plan for the RM strategy
- → WHO FENSA
- → 2023 Grants and contracts
- → 2022 Grants and contracts
- → 2021 Grants and contracts
- → 2023 Donations
- 2022 Donations
- → 2021 Donations
- Nouveau Centre fundraising campaign
- → Article about funding of cancer research #1
- → Article about funding of cancer research #2
- → Article about funding of cancer research #3



#### 1.3 Workforce

#### **Workforce inputs**

Main ambitions of the MTS 2021-2025:

- Attraction and building of talent
- Well-balanced geographical representation
- Equal treatment of all personnel regardless of race, gender, disability, religion or belief, sexual orientation, and age

#### KPIs:

- Gender balance at management level (Branch Heads and Deputy Branch Heads)
- Geographical diversity across the Agency and at management level

# Trends in IARC's Workforce by Branch and Employment Status

Table 7 illustrates the evolution of IARC's personnel since 2021, providing a breakdown of the number of Professional staff (P), General Service staff (GS), and Early Career and Visiting Scientists (ECVS) within each scientific Branch of the Agency.

In February 2024, the IARC workforce represented 359 personnel, including 98 Professional staff (P-staff, mainly scientists), 116 General Service staff (GS staff, technical, scientific, and administrative personnel), and 145 ECVS. Overall, the average number of staff (P and GS staff) of IARC during the current MTS period has decreased by 28.4 employees (-12%) compared with the former MTS period, with 240.4 staff members on average in 2016–2020 and 212 staff members on average in 2021–2024.

The management of the Agency considers that IARC was under major financial pressure during the move to

its new headquarters in 2021–2022, with limited resources for human resources development. After the successful move to the Lyon Gerland building in January 2023, IARC has been able to invest in additional scientific resources with +8 P-staff positions and +28 ECVS in 2024, compared with 2023.

During the MTS period (2021–2024), the number of staff members has increased in the GEM, EGM, and ESC Branches. The number of staff members has remained stable in the CSU and SSR Branches. It has decreased in the NME, ENV, and EPR Branches and in the Director's Office (DIR). This evolution raises questions about the scientific priorities of the Agency, including the willingness to invest in the CSU Branch, which corresponds to the first fundamental priority of the MTS.

The overall number of ECVS tended to increase (from 115 ECVS in 2021 to 145 in 2024) during the current MTS period, partly counterbalancing the reduction in the number of staff members. This means that the management ratio corresponding to the number of ECVS per P-staff has increased from 1.16 in 2021 to 1.48 in 2024. This evolution raises some questions about the relevant proportion of P-staff versus ECVS, to guarantee the relevant level of scientific supervision within the Agency.



Table 7. Evolution of IARC workforce according to Branches and categories of personnel (fixed term) 2021–2024<sup>10</sup>

Year	2021 (March)				2022 (March)				2023 (February)			2024 (February)				
Category	P Staff	GS staff	ECVS	Total	P Staff	GS staff	ECVS	Total	P Staff	GS staff	ECVS	Total	P Staff	GS staff	ECVS	Total
CSU	10	9	14	33	10	10	20	40	10	10	19	37	10	9	17	36
GEM	9	11	16	36	10	11	16	37	10	11	18	41	17	12	24	53
NME	16	22	22	60	12	21	34	67	12	19	37	66	10	18	40	68
ENV	8	6	15	29	6	6	19	31	6	5	17	29	8	5	17	30
EGM	5	6	14	25	6	8	16	30	6	8	9	23	6	7	13	26
EPR	16	12	25	53	13	9	29	51	13	9	21	43	12	9	20	41
ESC	10	7	5	22	9	9	9	27	9	11	6	29	14	12	11	37
LCB	1	4	0	5	1	4	0	5	1	4	1	6	1	3	0	4
SSR	14	36	2	52	15	35	2	52	15	36	3	55	15	36	2	53
DIR	10	10	2	22	5	5	2	12	5	4	1	10	5	5	1	11
Total	99	123	115	337	87	118	147	352	90	117	132	339	98	116	145	359

<sup>10</sup> Source: IARC/WHO, SSR (HRO) and LCB, May 2024.



Table 8 presents the number of departures (retirements and resignations) and the turnover rate of IARC's personnel in 2021–2024. On average for 2021–2023, about 14 staff members leave the Agency every year: one third of these personnel are retiring, and two thirds are resigning. The average turnover rate of IARC for this period is below 6%, which is a rather moderate level.

Table 8. Turn over within IARC for 2021–2024 <sup>11</sup>										
Year	2021	2022	2023	2024 (*)						
Number of staff retiring	2	5	7	2						
Number of staff resigning	12	8	7	6						
Turnover rate (%)	6.0%	5.6%	6.1%	3.4%						

#### Evolution of IARC's workforce according to gender and position

Table 9 presents the evolution and distribution of IARC's personnel by gender and management level from 2021 to 2024. As of February 2024, the overall composition of IARC's workforce reveals a majority of female employees, who constitute 68% of the total staff (Professional and General Service staff combined). Specifically, women make up 58% of the Professional staff (P-staff) and 78% of the General Service staff (GS-staff). At the P4 level, gender representation is evenly balanced; 50% of the 16 personnel are female. Similarly, gender parity is achieved among the leaders of IARC's Research Teams (as outlined in Section 4.1), with an equal 50/50 distribution between women and men.

At the management level, which includes Branch Heads and Deputy Branch Heads, women accounted for 42% of personnel in February 2024. By September 2024, at the executive level (P5 level and above), female representation had reached 30%, and this proportion showed gradual growth. Notably, the Agency's two highest leadership roles – the Director and the Director of Administration and Finance – are currently held by women from LMICs, specifically Brazil and India. This highlights IARC's commitment to fostering diversity and gender balance within its leadership structure.

Table 9. Evolution of IARC's workforce according to gender and position in 2021–2024 <sup>12</sup> Staff of IARC on fixed term positions (professional and general services)							
	Female		Male		Total		
Year	Number	%	Number	%	Number		
2021	141	64%	81	36%	222		
2022	132	64%	73	36%	205		
2023	139	67%	68	33%	207		
2024	145	68%	69	32%	214		
Management level (Branch Heads and Deputy Branch Heads)							
	Female		Male		Total		
Year	Number	%	Number	%	Number		
2021	9	41%	13	59%	22		
2022	8	40%	12	60%	20		
2023	8	38%	13	62%	21		
2024	8	42%	11	58%	19		

<sup>11</sup> Source: IARC/WHO, SSR (HRO), October 2024 (\* temporary figures for 2024). 12 Source: IARC/WHO, SSR (HRO), February 2024.



Executive level (P5 level and above) (September 2024)						
	Female		Male		Total	
Year	Number	%	Number	%	Number	
2021	2	18%	9	82%	11	
2022	1	11%	8	89%	9	
2023	2	20%	8	80%	10	
2024	3	30%	7	70%	10	

#### Geographical diversity across the Agency

According to the MTS 2021–2025, "as an international agency, IARC is fully aware of the need to ensure a well-balanced geographical representation among its scientific staff, and in the years to come will actively seek to enhance the representation of Participating States that are currently underrepresented". As of February 2024, IARC demonstrates substantial geographical diversity among its personnel, with **individuals from 62 nationalities** (staff and ECVS) contributing to its mission, including **representatives from 31 LMICs** (Table 11). All IARC Participating States are represented within the Agency's workforce, except for Denmark (one temporary staff member), Egypt (one associate officer), Saudi Arabia, and Qatar. Within the Agency's General Service (GS) and Professional (P) staff, the top three nationalities are France (115), the United Kingdom (12), and Italy (10). For GS staff positions, the WHO guidance states that these roles should, as far as possible, be filled by candidates recruited from the local commuting area of each office. This policy explains the high proportion of French personnel at IARC.

Among ECVS, the leading nationalities are France (27), China (10), and Brazil (8) (Table 11). Across all IARC personnel, the most represented nationalities include France, the United Kingdom, Italy, the USA, Brazil, Spain, Germany, China, the Islamic Republic of Iran, and India, all of which are IARC PS. IARC should promote the dissemination of job opportunities in underrepresented countries, particularly Japan and China (beyond ECVS roles), as well as Denmark, Egypt, Saudi Arabia, and Qatar. This effort would strengthen IARC's commitment to equitable geographical diversity and inclusivity within its workforce.

As of September 2024, IARC's executive management team (P5 level and above) comprises 10 employees of 9 different nationalities: India (2), United Kingdom (1), USA (1), Brazil (1), Croatia (1), France (1), Germany (1), Italy (1), and Ireland (1). Of these, all countries except Croatia are IARC PS. Notably, European nationalities account for two thirds of the representation at the executive level. To strengthen geographical diversity and inclusivity within its leadership, IARC should consider a better representation from Group 1 PS in Asia, particularly China and Japan, at the executive level. This would enhance the global representation of its leadership and reflect the Agency's commitment to balanced geographical representation.

Table 10. Top 10 nationalities within IARC personnel (Staff and ECVS) <sup>13</sup>					
Nationality	Number of personnel				
FRA	142				
UNK	19				
ITA	14				
USA	13				
BRA	12				
SPA	12				
DEU	12				
CHN	10				
IRN	10				
IND	9				

 $<sup>^{\</sup>rm 13}\,\text{Source}{:}\,\text{IARC/WHO},\,\text{SSR}$  (HRO) and LCB, February 2024.



Tabl	e 11. Per	sonnel of	IARC accor	ding to	nationalities <sup>14</sup>
Nationality	P Staff	GS Staff	Total Staff	ECVS	Total IARC personnel
ALG			0	1	1
AUS	1	1	2	2	4
AUT	1	1	2		2
BEL	2	2	4	1	5
BEN			0	1	1
BLR			0	1	1
BOT			0	1	1
BRA	4		4	8	12
CAM			0	1	1
CAN	3	2	5	2	7
CHN			0	10	10
COL	4		4	1	5
COR			0	1	1
CRO		1	1		1
CUB		1	1		1
CZH		1	1		1
DEU	3	1	4	4	8
FIN	1		1		1
FRA	39	76	115	27	142
GHA			0	2	2
GRE	1		1	4	5
GUT			0	1	1
HUN	1		1		1
IND	1	1	2	7	9
IRN	2		2	8	10
IRE	2	2	4		4
ITA	6	4	10	4	14
JPN	_		0	3	3
KOR	1		1		1
LEB	1		1		1
LTU	1		0	1	1
MAA	1		1	1	2
MAL			0	1	1
MOR			0	1	1
NEP			0	3	3
NEZ			0	2	2
NIE	4	4	0	3	3
NLD	1	1	2	2	4

<sup>14</sup> Source: IARC/WHO, SSR (HRO) and LCB, February 2024.



NOR		1	1	1	2
PAK			0	1	1
PHL		2	2		2
POR	1	1	2	1	3
PSE	1		1		1
ROM	3		3		3
RUS	2		2		2
RWA			0	1	1
SOA			0	1	1
SPA	4	1	5	7	12
SRL	1		1		1
SVK		1	1		1
SWE	1	1	2	2	4
SWI	1	1	2		2
THA		1	1	1	2
TUN		1	1		1
TUR			0	1	1
UGA		1	1		1
UKR	1		1		1
UNK	4	8	12	7	19
USA	4	2	6	7	13
ZIM			0	1	1
TOTAL	98	115	213	135	348

# Recruitment process

IARC promotes all its professional opportunities on its <u>official website</u>. As part of the World Health Organization (WHO), all IARC announcements are also automatically shared on the WHO LinkedIn page, enhancing visibility and outreach. To attract highly qualified candidates, IARC is establishing a network of international and multinational organizations to effectively communicate with focal points for disseminating vacancies, tailored to the nature of the work and the targeted organizations.

IARC follows a sophisticated and transparent recruitment process that involves multiple steps and various parties. As summarized in the flowchart below, the five main stages of this process are:

- 1. Advertising the requisition, dissemination and outreach
- 2. Shortlisting and clearance
- 3. Testing and scoring
- 4. Interview
- 5. Selection report and approval.





IARC recruitment process flowchart.15

The official target duration for completing recruitment processes within IARC is 15 weeks. However, during the first 2 years of the MTS (2021–2022), Branch Heads reported that some recruitments took up to a year to finalize. Due to the absence of KPIs on recruitment for that period, it is not possible to verify these claims. According to the IARC HRO, several factors contribute to delays in recruitment, such as extending the announcement duration to improve outreach, and the availability and responsiveness of all parties involved in the process.

Data for 2023 and January–August 2024 (Table 12) provide insights into the recruitment process. Over this 20-month period, IARC conducted 57 recruitments and 63 appointments. The average duration for recruitment during this time was 19 weeks. Notably, the recruitment timeline improved significantly, from an average of 24 weeks in 2023 to 16 weeks in 2024. This improvement is attributed to the addition of an Associate Human Resources Officer specializing in recruitment at the end of 2023. In 2024, the number of recruitments has increased compared with 2023, and the average recruitment duration is approaching the target of 15 weeks. This progress highlights the positive impact of enhanced HRO resources and underscores the potential for further optimization of the recruitment process.

Table 12. KPIs on IARC recruitments for 2023 and mid-2024 <sup>16</sup>										
	20:	21	202	22	20	23		August 24	тот	ΓAL
Type of staff	GS	Р	GS	Р	GS	Р	GS	Р	GS	Р
Number of recruitments	-	-	-	-	10	12	18	17	28	29
Total all staff	_		_		2	2	3	5	5	7
Number of appointments	-	-	-	-	12	15	17	19	29	34
Total all staff	_		_		2	7	3	6	6	3
Average number of weeks	-	-	-	-	28 weeks	21 weeks	18 weeks	14 weeks	22 weeks	17 weeks
Total average number of weeks	-		-		24 w	eeks	16 w	eeks	19 w	eeks

<sup>15</sup> Source: IARC/WHO, SSR (HRO), September 2024. 16 Source: IARC/WHO, SSR (HRO), September 2024.



# Equity and Diversity in the Agency

According to the MTS 2021–2025 document approved by IARC governance in 2021, "respect for equality and diversity are essential to the success of IARC's work, because these principles promote an environment of inclusiveness, where innovation and scientific creativity can thrive and where differences are recognized, respected, and valued. These important core values will be promoted, and equal treatment of all personnel will be ensured regardless of race, gender, disability, religion or belief, sexual orientation, and age". To reinforce this commitment, IARC appointed an Equity and Diversity Officer in 2018 and established the Equity and Diversity Advisory Group (EDAG). These initiatives aim to:

- Promote understanding of equity and diversity in the workplace among all personnel,
- → Collaborate with relevant colleagues (e.g. HRO, ASO, Occupational Health, Staff Association) to share best practices and challenge inequality and discrimination,
- → Alert the Director to existing or emerging issues requiring attention,
- → Provide an annual report summarizing key concerns for discussion with the Senior Advisory Team on Management (SAT).

In line with the UN Disability Inclusion Strategy and the WHO initiative on Promoting Diversity, Equity, and Inclusion, IARC launched its Equity, Diversity, and Inclusion Strategy in 2022. This comprehensive strategy, supported by an action plan for 2022–2026, aims to address gaps in policies and promote a more diverse, inclusive, and equitable culture.

# Key milestones include:

- Training and awareness: Launch of training programmes in 2021, including workshops on implicit bias, prevention of sexual harassment, conflict management, and leadership development. Development of an IARC Internal Committees Checklist to incorporate equity considerations into meetings and conferences.
- Infrastructure improvements: Relocation to new IARC headquarters in 2023, designed to meet French accessibility regulations, ensuring compliance for individuals with physical, sensory, and cognitive disabilities. This move aligns with IARC's efforts to create a more inclusive workplace and support the recruitment and retention of persons with disabilities.
- Promoting gender equality: Introduction of the IARC Award for Women in Cancer Research, recognizing excellence in the field. In 2022, Professor Cristina Stefan received the award, followed by Professor Neerja Bhatla in 2023.
- Community engagement: Organization of LGBTQ+ social events in 2023 and 2024 to foster community and dialogue among personnel.
- **Disability inclusion:** A Disability Awareness Survey in 2022 to identify barriers and opportunities for making IARC a more disability-inclusive workplace.

Although IARC does not currently provide statistics on personnel with disabilities, its initiatives – such as the improved accessibility of its headquarters – are designed to facilitate the employment and inclusion of individuals with diverse needs. The Agency has also taken tangible steps towards promoting equity across multiple dimensions, including gender, geographical representation, sexual orientation, and education diversity.



# Equity and Diversity Advisory Group

2021-2023 activities

# **Mission**

The Equity and Diversity Advisory Group (EDAG) was established to address diversity and inclusion challenges within IARC. As an advisory body, EDAG works closely with IARC leadership to foster an inclusive environment where

every individual has equal access to growth opportunities and a work environment free from discrimination. EDAG's mission focuses on:

- Fair treatment: Ensuring equitable treatment of all IARC staff.
- Development support: Enabling all personnel to reach their full potential.
- Inclusive culture: Fostering an environment where diversity and inclusivity are embedded within the Agency's culture.
- Equal opportunity: Promoting equitable access to learning and career development.
- Anti-discrimination policies: Ensuring that IARC's policies and procedures align with antidiscrimination principles.
- Awareness and training: Equipping personnel to recognize, challenge, and address inequality and discrimination in the workplace.

# **Activities during the MTS period 2021-2024**

Throughout the 2021-2024 period, EDAG led various initiatives to strengthen diversity, equity, and inclusion at IARC. These activities span recommendations on internal practices, events to foster inclusivity, and training sessions to raise awareness and support equitable practices.

#### Recommendations for IARC-based initiatives

During the 2021-2023 period, EDAG received several requests for recommendations on inclusion, diversity, and equity practices. These included:

- 1. The Biostatistics/Bioinformatics Working Group requested a recommendation on the use of DataCamp for training at IARC.
- 2. HRO requested a recommendation on the proposed participants for G-Force.
- 3. The IARC Monographs programme requested feedback on its form used to collect information on Working Group participants.
- **4.** LCB requested a recommendation on providing information about current challenges for ECVS from specific countries.

# Membership

In 2023, EDAG comprised a dedicated team of members who volunteered to contribute to IARC's diversity and equity goals.

Membership is approved by the IARC Director, with contributions spanning diverse areas of expertise.

Members (2023): Asiedua Asante; Komodo Matta; Isabelle Soerjomataram; Arunah Chandran; Harriet Rumgay

→ Several members concluded their terms in 2023, including the EDAG Chair, Shama Virani.

Moving forward, the group will be co-chaired by Asiedua Asante and Arunah Chandran, ensuring continuity and leadership into 2024 and beyond.



#### 2021 Activities

- LGBTQ+ event: In May 2021, EDAG and the Staff Association hosted IARC's first LGBTQ+ event, a virtual gathering for LGBTQ+ staff and allies to share experiences and discuss working at IARC. With 60 attendees, the event was a safe space for open dialogue on inclusivity. The overall conclusion was that IARC is an open, progressive environment and LGBTQ+ staff have not encountered any apparent discrimination in the workplace.
- Implicit bias training: After feedback from the IARC Open Forum on diversity, EDAG partnered with the IARC Learning Team to organize a 1.5-hour implicit bias workshop led by Professor John Antonakis. The session addressed subtle biases that affect career progression, was attended by 170 participants, including Branch Heads and Deputy Branch Heads, and received positive feedback for its evidence-based approach.
- Respectful Workplace Day: Held on 2 December 2021 in collaboration with the Respectful Workplace Initiative team, the event included presentations on the new WHO Policy on Preventing and Addressing Abusive Conduct (PAAC) and discussions on reducing unconscious bias. Insights from these sessions informed plans to create posters for promoting respectful workplace values.
- Gender equality plan: EDAG was tasked with drafting a gender equality, diversity, and inclusion strategy to support European Commission grant application requirements. The team drafted the strategy and action plan, setting a foundation for IARC's commitment to gender equality and diversity.

## 2022 Activities

- IARC Award for Women in Cancer Research: The award, launched by the Initiative to Highlight Women in Science, aimed to recognize outstanding women scientists (see the box). The first award was presented to Dr Cristina Stefan in May 2022 for her contributions to global cancer research.
- Survey on physical disability: In July and August, EDAG conducted a survey to assess awareness, needs, and experiences related to physical disability within IARC. The survey received 53 responses, providing critical insights:
  - Awareness: Respondents highlighted a lack of information on accommodation measures available at IARC, suggesting the need for clearer communication and accessible resources.

# Addressing the gender gap in Science: Focus on the IARC Award for Women in Science

Despite growing numbers of women pursuing university degrees in medical and scientific fields, women remain underrepresented in science, especially in senior leadership roles. Although gender balance has improved at the postdoctoral level, disparities persist in certain research fields, such as data science. Moreover, many women encounter a "glass ceiling", which limits their progression to top positions in research leadership.

Launched in 2022, the IARC Award for Women in Cancer Research aims to honor women who have made outstanding contributions to cancer research. Recognized contributions may include scientific discoveries, implementation of impactful practices, and leadership within their field. The award also seeks to raise awareness of the contributions of women in science and encourage greater visibility of women in research and leadership.

Nominations are reviewed by EDAG and validated by the Director before being presented to a committee of IARC staff for final selection. The awardee is invited to IARC to receive the award in person, participate in a public lecture (also live-streamed on IARC's YouTube channel), and engage in a lunch and discussion session with junior scientists and other staff to encourage knowledge sharing and mentorship. The award event is promoted through IARC town hall meetings, the Agency's news pages. newsletters, and social media platforms, ensuring widespread visibility and engagement across IARC and beyond.



- Inclusivity suggestions: Recommendations included more inclusive recruitment announcements, enhanced support for staff needs, and education sessions on disability awareness.
- Personal and familial experiences: Many respondents shared challenges related to disability, detailing its impact on their lives and emphasizing barriers they face both personally and professionally.
- Disability inclusion town hall and WHO Affinity Group presentation: After the survey, EDAG hosted a town hall meeting. The WHO DEI Project Manager presented on the WHO Affinity Group, Embracing Disability, which promotes inclusivity for those with disabilities at WHO. With 117 attendees, this event shared best practices and reinforced IARC's commitment to inclusivity in alignment with WHO initiatives.

#### 2023 Activities

- Second Women in Science Award: In October 2023, IARC awarded Professor Dr. Neerja Bhatla, a distinguished gynecologist and researcher from India, the second Women in Science Award.
- Disability Inclusion Working Group: In response to interest from the 2022 survey, a working
  group was formed to explore disability inclusion at IARC. A key outcome was the compilation
  of resources on the WHO UNDIS webpage, forming the basis for future inclusion activities.
- Engagement with WHO DEI initiatives: Following the "Let's Talk" Survey Phase 1, IARC invited
  a WHO DEI Initiative speaker to share insights on the "Listen, Learn and Act Together" project
  phases. Although direct participation was limited, IARC staff engaged in related WHO disability
  inclusion seminars, highlighting IARC's commitment to continuous DEI learning.

# Challenges and recommendations

Although EDAG has made notable strides in advancing equity and diversity at IARC, it faces several key challenges that affect its ability to implement comprehensive initiatives effectively. The following are the primary areas of concern and the corresponding recommendations:

- Resource constraints: The budget reduction in 2018–2019, which affected essential
  programmes such as Fellowships and the Summer School, continues to affect EDAG's available
  funding for diversity and equity initiatives. To mitigate this, EDAG recommends exploring new
  funding opportunities, potentially from external sponsors, to ensure stable support for critical
  programmes.
- Data collection and benchmarking: One of the primary challenges is obtaining detailed diversity data beyond gender and geographic distribution, which has limited the ability to benchmark and evaluate diversity trends over time. This gap is largely due to HRO's workload, which affects the availability of data for diversity tracking. EDAG proposes that limited access to SAP data be granted for aggregated analysis of key diversity metrics.
- Feedback mechanisms: Gathering staff feedback on equity-related issues remains challenging. EDAG has suggested using REDCap for anonymous feedback collection; however, further discussions with the administration are needed to define how this feedback can be integrated into actionable policy adjustments.
- Membership retention and engagement: The voluntary nature of EDAG membership, coupled
  with additional responsibilities, has made recruiting and retaining engaged members difficult.
  This challenge is particularly acute as EDAG activities expand, necessitating continuous



commitment from members. In addition, since the departure of Dr Shama Virani as Equity and Diversity Officer at the end of 2023, a standardized process for nominating a successor has been lacking, alongside clear terms of reference for the role. To improve engagement, EDAG suggests clarifying member roles and mandate lengths, and aligning EDAG's work with broader IARC goals, which could make participation more manageable and impactful.

• Early Career and Visiting Scientist (ECVS) engagement: EDAG recommends that ECVS personnel be given opportunities to host informal "Meet the Scientist" sessions after the Governing Council and Scientific Council sessions. Such sessions would enable junior staff to interact with high-level scientists, enriching their learning experience at minimal cost.

# **Future Perspectives**

Looking to 2024, EDAG aims to expand its activities through several initiatives:

- → Future of the IARC Award for Women in Cancer Research: Given the limited resources available for this initiative (see "Challenges"), EDAG has requested that the IARC administration establish a dedicated budget line to ensure the Award's sustainability. For the 2023 Award, travel costs for the recipient were covered by EPR under exceptional circumstances. However, due to the absence of a dedicated budget line and the lack of staff with allocated time for award management, EDAG has decided to postpone the 2024 IARC Award for Women in Cancer Research until sustainable funding is secured.
- → Workshops on equity and diversity: EDAG will organize a series of seminars featuring experts from other institutions to share best practices, discuss solutions to equity and diversity challenges, and explore ways to apply these practices at IARC.
- → Support for new personnel: EDAG will partner with the Fellowship Office to enhance onboarding for new ECVS, focusing on housing access, integration into IARC, and community immersion.



# **Infrastructure inputs**

Main ambitions of the MTS 2021-2025:

- → IARC's new building (Nouveau Centre) in Gerland
- Support of the laboratories and biobank's sustainability
- Digitalization, open science and data

#### KPIs:

- Nouveau Centre in Gerland investment and operating costs (case study)
- → New-generation biobank (case study)

**Source:** SSR (ASO and ITS), LSB (Biobank)

# 1.4 Infrastructure

The work infrastructure of IARC has significantly evolved during the period of the MTS 2021–2025, with the move of the Agency to its new headquarters in Lyon Gerland (case study), the new-generation biobank in the new IARC premises (case study), and the implementation of the IT roadmap.

The Scientific IT platform and data protection within IARC are presented in the outcomes section of the report (see "Open Science", part 5.4).

# Nouveau Centre Case study

# **Structure**

# Governance framework

The governance for building the new IARC headquarters (called during the project phase the "Nouveau Centre") relies mainly on the following committees:

- The steering committee with the funders Lyon Métropole, French government, Auvergne Rhône-Alpes Region, and the City of Lyon,
- The technical committee with the Lyon
   Métropole (owner of the building) and the leader of the construction consortium (Demathieu-Bard),
- The Nouveau Centre project board (internal IARC committee) for coordination of the move to Lyon Gerland.

## Summary

The construction of the "Nouveau Centre", the new IARC headquarters building, was officially completed on 28 October 2022, after 27 months of work (excluding preparation) and the collaboration of more than 60 companies. IARC's equipment and furniture were moved into the new building as planned, including the delicate transfer of the Biobank and its 6 million biological samples. IARC personnel gradually moved into the new building in January and February 2023. The new IARC headquarters building was officially inaugurated on 12 May 2023, at the end of the GC65 session, with more than 500 participants.

Located at 25 avenue Tony Garnier in Lyon's 7th district, the new IARC building is laid out over six floors offering 11 500 m2 in total, which represents an almost 20% increase in capacity compared with the previous premises. It provides attractive offices (5000 m2), meeting rooms (1100 m2), and modern laboratories (3000 m2). It will enable IARC to expand its workforce to at least 500 personnel. It will also contribute to reducing IARC's ecological footprint, thanks to its eco-friendly design.



# **Links with WHO**

As part of the Nouveau Centre project, IARC set up two kinds of collaborations with WHO. IARC took advantage of the advice of WHO headquarters based on the experience about their new offices in Geneva, to prepare for the move and the space planning in the new building. IARC also established a collaboration with the WHO Academy, which will inaugurate its building in Lyon Gerland, near IARC, in December 2024. This collaboration enabled sharing of good practices for the building management, technical terms of reference and contracts, as well as service providers, such as maintenance and security.

# Other key partners

The United Nations Department of Safety and Security (UNDSS) ran an audit of IARC's new building in September 2022, to ensure security and compliance with UN rules.

IARC also benefited from the United Nations "Office Space - Standards and Guidelines - A tool for implementing a Hybrid Workplace Model at UN Offices", in order to define and implement the space planning and the organization of work in its Gerland building.

#### Resources

The total investment supported by the French authorities for the building construction exceeds €60 million (Lyon Métropole, €19 million; French government, €17 million; Auvergne Rhône-Alpes Region, €14.2 million; and land provided by Ville de Lyon, €13 million). The fundraising campaign (> €2 million of financial and in-kind donations), the sale of the Grange Blanche buildings (€1.5 million), the GC Special Funds (€1 million loan), and other funding have enabled IARC to make significant investments in new equipment and furniture.

The financial summary of all investments to build the new IARC headquarters is not yet available, because the real estate contract is not closed. The overall operation should exceed €65 million of investment supported by the French authorities, as the hosting country of IARC. Thanks to the convention signed on 17 October 2022 by IARC and the owner, Métropole de Lyon, the building is made available to the Agency free of charge for a period of 30 years, which may be extended. The estimated minimum rental value corresponding to this service provided by France for the IARC building is €2 700 000 per year.

Building management is not yet optimized in IARC offices, because the Building Operation System is not yet fully operational. This tool will enable the management of 6000 points in the building. At this stage, evaluation of the main operating items indicates that annual energy expenditure represents €1.8 million, maintenance €400 000, and security €350 000.

# **Key Performance Indicators (KPIs)**

According to the IARC Administrative Services (ASO), the main KPIs about the new headquarters are under definition and they should deal with:

- the building occupancy rates,
- → the events organized on the ground floor, as well as the use of the auditorium and meetings rooms for Open Science,
- → the **building consumption and operating costs**, especially energy and water.

Based on preliminary data, the IARC building is occupied on average by 200–250 people each day. This corresponds to two thirds of IARC personnel, in particular due to teleworking and duty trips. Offering 500 workstations in total, the new IARC headquarters can support a significant growth of the Agency in the coming years.

After its inauguration in May 2023, the new IARC building welcomed 91 events in 2023 (corresponding to the May-December 2023 period), including 9 events organized by IARC partners. During the first semester of 2024, IARC hosted 61 events in its new building, including 2



events organized by IARC partners. IARC expects to have 120–130 events in 2024. This represents a significant increase compared with the former building in Lyon Grange Blanche, which hosted 80–100 events per year. IARC is working on guidelines regarding the rules and conditions for hosting external events. Those figures are a good illustration of the attractiveness of the new IARC headquarters and the implementation of its Open Science strategy.

# **Alignment with IARC MTS 2021-2025**

Smooth move to the Nouveau Centre: According to the MTS 2021-2025: "the move of IARC to its new headquarters building, the Nouveau Centre - expected to occur in 2022 - will enable IARC to transition smoothly to a state-of-the-art, eco-friendly Agency, embracing and living the concept of Open Science. The smart building will provide an inspiring environment for scientific collaboration and for advancing global cancer research. Its physical structure will emphasize transparency and echo an Open Science concept. The Nouveau Centre will host cutting-edge technologies for meeting management, digital and flexible workplaces, collaborative workspaces, cloud-based scientific data management, and a modern biobank and laboratories... In Nouveau Centre, conference services and laboratory services will be provided centrally to research teams. The Nouveau Centre's proximity to the future WHO Academy may result in further synergies and opportunities to share resources".

# Integration to the IARC Project Tree

The project on the new IARC headquarters is part of the Level 2 Objective of the IARC Project Tree "Strengthening the efficiency and effectiveness of the Agency's research and collaboration", and it contributes to the Level 3 Objective: "Enable strategic vision and implementation, including management of financial, human, information, and infrastructure resources, to enable and support the effective delivery of the Agency's mandate".

→ Delivery of the new IARC headquarters was delayed, mainly due to delays in the construction work and the impact of the COVID-19 pandemic. Once the building was completed, the move of IARC to the new headquarters can be considered a success in every respect. Moving the laboratory equipment and the 6 million biobank samples was a logistical challenge that was handled particularly well. The move to Gerland was on time and on budget. The IARC teams took possession of the new premises at the beginning of 2023, benefiting from new working conditions (new furniture, modern meeting rooms), up-to-date laboratories, and an attractive cafeteria. In addition to the WHO Academy, numerous contacts have been established by IARC with Lyon Gerland partners (e.g. IRT Bioaster, SFR Biosciences de Lyon, IBCP) to take advantage of new synergies within the Lyon Gerland Biodistrict.

# Main challenges and future perspectives

The three main challenges for the new IARC headquarters are the following:

- During the first year of commissioning, the 6000 defects, observations, and remarks recorded
  in the joint inspection report were fixed and/or addressed. Morethan 300 additional
  malfunctions were reported to the owner and then corrected within the framework of the
  warranty period. The warranty has been extended by six months on all heating, ventilation, and
  air conditioning installations. In addition to these problems, there are still some malfunctions in
  the laboratories, which impact IARC's research activities.
- The new headquarters should contribute to make IARC an eco-friendly Agency. Energy costs
  for the new building are of the same order of magnitude as for the previous one, but over a
  20% larger surface area. A major problem IARC is currently facing concerns the three-fold



increase in electricity costs during the past months. To face this challenge on energy consumption, IARC needs to finalize it Building Operating System (BOS) and more widely its policy for a sustainable research agency.

The third challenge is about the cooperation with the WHO
Academy. After the inauguration of this new WHO building in
December 2024, the two WHO entities should reinforce their
synergies on shared services (e.g. occupational physician)
and shared service providers (e.g. security, maintenance), as
well as the relationships with local and national authorities.

#### For more details

- → IARC press release
- → Press article Lyon entreprises
- → Press article Lyon Capitale
- → Nouveau Centre opening ceremony



# Open access biobank

Case study

# **Overview**

# Objectives and target audience

The <u>IARC Biobank</u> (IBB) is a centralized biological resource storage facility for samples collected from studies conducted worldwide by IARC in collaboration with international partners. The Laboratory Support, Biobanking, and Services (LSB) unit is responsible for the management of the IBB, services in pre-analytical sample processing, and shipment.

Biological resources consist of human tissues, cells, biological fluids or derived products and associated data. Sample collections are based on common characteristics (e.g. sera from individuals from a population-based study; a clinical collection of breast cancer tissues). Associated data include anonymized data associated with biological samples, sample annotations, and data on sample quality.

As a public international organization funded by a collaborative research mandate with the mission of promoting international collaboration in cancer research at the international level, IARC wants to ensure that the biological samples stored in its biobank are valued and widely used at the international level. Thus, IBB samples are available for research through projects consistent with IARC scientific objectives, standard practices,

# **Summary**

The IARC biobank is unique on the international scene because of its size (>6 million biological samples) and the diversity of its biological resources (50 different types of biological material) and geographical origin (90 supplying countries). It feeds more than 60 international scientific projects every biennium involving more than 250 partners. The biobank relies on a team of 12 professionals. Its operating budget is €0.6 million, it is publicly funded with 60% of its budget provided by IARC Participating States and 40% from research grants. The IARC biobank, at the national level, is a member of the 3CR Network, the <u>French network of biobanks</u>. The IARC biobank also participates in several international research programmes, in accordance with IARC's mission. To remedy the under-representation of biological resources in low- and middle-income countries (LMICs) in the field of research, IARC has been coordinating the biobank and population cohort network BCNet since 2013, in collaboration with the NCI (Center for Global Health, NCI, NIH, USA) and 54 institutions representing 25 countries.

In 2022, the IARC Biobank moved successfully from the Lyon Grange Blanche building to the new IARC headquarters in Lyon Gerland. These new premises represent a unique opportunity for the technological evolution of the IARC Biobank towards a new generation of biobanking, as the storage capacity increased to 10 million biological samples and it meets all the standards and state-of-the-art rules in the field of biobanks. It occupies over 1550 m<sup>2</sup> of the first basement of the new building, with more than 1000 m<sup>2</sup> for secure storage facilities. A state-of-the-art liquid nitrogen facility is set up with new ultra-modern liquid nitrogen tanks controlled and monitored through a smart management system of the cryogenic rooms. Freezers rooms are equipped with new freezers

In January 2024, the IARC biobank successfully applied to the IBIsA French programme, to reinforce its quality management and to strengthen its open science collaborations in the local, regional, national and international research landscape. Following this initiative, the objective of the management of the IARC biobank is to implement in the medium-term the ISO 20387 certification for the unique research infrastructure.

and IARC/WHO legal and ethical standards. The principle of access to samples is based on the best possible scientific use, taking into account the interest of the participants and the public



benefit. In particular, researchers and managers of IARC biological collections are encouraged to identify new uses and potential users of biological resources and to ensure that researchers working on cancer are informed of advances in scientific research generated through these collections.

IBB users are internal (IARC research groups) or external collaborators: a procedure for accessing IBB samples and wide range of services provided is available <u>online</u> and as shown below.



IT Infrastructures for Biobanks

eB3Kit, BIBBOX, BCNet Catalogue



Sample and Data Collection

Mobile data collection (ODK)



LIMS, MTA, DTA, MIABIS



**Bioinformatics** 

Galaxy, Galaksio



Ethical, Legal and Social Issues

Informed consent, MTA/DTA, guides, templates, recorded webinars



**Ouality and Sustainability** 

Best practices and standards, SOPs, protocols



Main resources on the website of the IARC biobank.

# History and evolution

The IARC Biobank (IBB) was initially housed in a building constructed in the 1960s. From the early 1970s to the late 1990s, IARC samples were stored in freezers and cryogenic vessels scattered throughout the research laboratories and in the basement of the main IARC building, with no overall storage management system. The Biological Resource Centre (BRC) was built in 1995, mainly to house the 34 cryogenic tanks needed to store the 3.5 million samples from the EPIC study.

In the early 2000s, the sample storage units were reorganized as the number of collections grew. A dedicated storage area was allocated for 40 freezers (-80 °C, -40 °C, and -20 °C). A basic alarm system to monitor freezer temperatures was installed, replaced in 2012 by a professional temperature monitoring system. Over the years, more than 4.3 million blood-derived products, tissues, and cell lines were stored in a total of 38 cryogenic tanks, and more than 1.5 million samples were stored in 150 freezers (blood derivatives, tissues, body fluids, exfoliated cells, nucleic acids, etc.) and at room temperature (bloodstains dried on filter paper, hair, nails, tissues, etc.).

Because the IARC buildings had become obsolete and dilapidated, a project to build a new IARC headquarters building, promoting Open Science, was launched in 2011 and completed by the end of 2022. The new biobank, with an increased capacity of 10 million biological samples, is located in these new premises. The move was the main challenge during the current MTS period. The transfer of the 6 million samples to the new biobank was a success, managed in 10 days. However, it took 6 months of preparation and the training of 45 people to run this transfer successfully.

This new biobank infrastructure meets all applicable regulatory and normative requirements and is built and operated according to the best practices in the field. This transition to new premises is accompanied by a reinforced quality approach to guarantee and display the high quality of research activities carried out at IARC and the Agency-wide standardization of biological sample management.

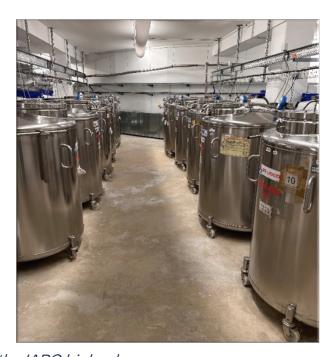


#### Current biobank infrastructure

The IBB is made up of more than six million biological samples of a wide variety of natures, collected in many countries and stored at temperatures ranging from ambient temperature ( $\sim$ 50 m<sup>2</sup>), down to  $\sim$ 196 °C in 38 liquid nitrogen tanks ( $\sim$ 400 m<sup>2</sup>) and 150 freezers ( $\sim$ 550 m<sup>2</sup>).

Planning for the long term, a dedicated space ( $\sim$ 65 m²) is allocated for the extension of the storage capacity at  $\sim$ 80 °C through the acquisition of a fully automatic  $\sim$ 80 °C freezer.





Liquid nitrogen tanks of the IARC biobank.

All sample storage units are equipped with a real-time temperature monitoring system that generates and sends alarms in the event of significant temperature deviations. An on-call system by members of the biobank and laboratory staff enables them to intervene within the hour in the event of an alarm being triggered and the temperature of a piece of equipment rising.

The IBB manages and operates a platform of pre-analytical services such as:

- Design and setup of new collections of biological samples,
- Receipt and storage of samples,
- Inventories of biological samples,
- Robotic and manual DNA/RNA extraction or biofluids aliquoting,
- DNA/RNA quantification by spectrophotometry or fluorimetry,
- Shipping and distribution of biological samples in accordance with national and IATA regulations,
- Computerized management of samples with an internal standardized sample management system developed especially for the biobank (SAMI).





IARC biobank platform of pre-analytical services.

For all pre-analytical services offered, the IBB follows these standards, recommendations, and norms:

- Common Minimum Technical Standards and Protocols for Biobanks Dedicated to Cancer Research (IARC Technical Publication No. 44),
- IATA Dangerous Goods Regulations (DGR),
- Procedure for the preparation/conservation of human biological samples intended for research and procedure for importing and exporting human biological samples intended for research according to the Jardé law published on 17 November 2016.

# **Structure**

#### Governance framework

The IBB governance is ensured by a Biobank Steering Committee (BSC) and an Ethics Committee. The Biobank Steering Committee consists of 12 experts, whose responsibilities are to:

- Provide advice in terms of strategic development of Biobank activities in line with the IARC's MTS 2021–2025.
- Provide strategic and technical advice to IARC research Branches in (i) their development of new collections of biological samples, (ii) their initiatives in terms of biobanking activities, and (iii) the recovery of biobanking costs in collaboration with the head of the biobank.
- Anticipate and plan for IARC's needs and opportunities in the broad area of biological specimen collection and use, including identifying infrastructure and human resource needs,
- Ensure compliance of biobank activities with international ethical standards.

# Links with WHO

The IBB is a faculty member of the WHO Academy. The members of the IARC Biobank are involved in the current development of a global digital course on "Managing Medical Research Infrastructures" to be released by the WHO Academy in the coming months.

The IBB members interact with WHO headquarters to contribute to the WHO Global Initiative for Childhood Cancer (GICC), and they collaborate with some WHO national offices in Asia (Nepal, Indonesia, Philippines, and Malaysia) for capacity-building and training related to research infrastructure.



The IARC Ethics Committee consists of 11 experts (including nine external members), and its role is to provide ethical reviews of all IARC scientific project proposals under its purview and to ensure that ethical processes are well respected. The Ethics Committee reviews, approves and monitors all research projects coordinated by or in which IARC scientists participate. No IARC project can be launched without the authorization of the Ethics Committee. In particular, ethics committee approval is required for all research proposals involving individuals recruited specifically for the study, collections of human biological material, and/or data allowing the identification of individuals, and this for any study in which IARC is involved in whatever capacity.

#### International collaborative network

In France, the IARC biobank is a partner of the Cancéropôle Lyon Auvergne Rhône Alpes (CLARA) on regional projects. At the national level, it is a member of the 3CR network, the <u>French network</u> of biobanks.

The members of IARC biobank coordinate or contribute to several international networks related to the development of biobanking, as described below. Other partners of the IARC biobank include collaborations with Jiao Tong University in Shanghai, Chinese CDC, the China National GeneBank, the Saudi Arabia Minister of Health, the Qatar Precision Health Institute, the international society for biobanking (ISBER), Columbia University (NY, USA), and others.

With regard to infrastructure-related research, the IARC Biobank represents IARC within the International Organization for Standardization (ISO, TC276: Biotechnology), the European Open Science Cloud Association (EOSC), and the pan-EU BBMRI-ERIC consortium (Biobanking and BioMolecular resources Research Infrastructure-European Research Infrastructure Consortium; (BBMRI-ERIC). BBMRI, in collaboration with IARC, recently launched an initiative to better understand the world of paediatric biobanks (EPTRI).

IARC also coordinates the biobank cohort network BCNet created by IARC in 2013, in collaboration with the NCI in the USA (described in 3.2).

In addition to these biobanking networks, the IARC biobank has been involved in several international research programmes or consortia, including:

- Bridging Europe-Africa Biobanking and biomedical research (B3Africa). Horizon 2020, EU grant agreement ID: 654404; (01/07/2015 30/12/2018); IARC budget: €365 000.
  - → B3Africa implemented a cooperation platform and technical informatics framework for biobank integration between Africa and Europe. The collaboration harmonized the ethical and legal frameworks, where available, the biobank data representation and bioinformatics pipelines for sharing data and knowledge among biobanks and allowed access for researchers from both continents.
- Implementation and operation of the gateway for health into the Biobanking and BioMolecular resources Research Infrastructure - European Research Infrastructure Consortium (ADOPT BBMRI-ERIC). Horizon 2020, EU grant agreement ID: 676550; (01/10/2015 - 31/03/2019); €113 000.
  - → The ADOPT BBMRI-ERIC boosted and accelerated the implementation of pan-EU research infrastructure BBMRI-ERIC and its services. It launched the construction of key Common Services of the Research Infrastructure as required for ESFRI-projects, reflecting the targets of the European Research Area (ERA). ADOPT BBMRI-ERIC provided the interface or the access to large volumes of standardized samples and data.
- Twinning for the Armenian Research Infrastructure on Cancer Research (ARICE). EC REA, grant agreement ID: 952417; (01/09/2020 31/08/2023); €147 000.
  - → This project significantly strengthened the scientific and technological capacity of the linked institutions, with a principal focus on the Yerevan State Medical University



(YSMU), Armenia. It enhanced the YSMU research infrastructure development for clinical genetic research, in particular targeting chronic, non-communicable diseases such as cancer.

- Impact of COVID-19 on Cancer (IMCOCA). Prévention santé Cancéropôle Lyon Auvergne-Rhône-Alpes (CLARA), (01/02/2021-01/06/2023); €12 000.
  - → IMOCA investigated the impact of the COVID-19 pandemic on cancer care in the Auvergne-Rhône-Alpes Region, showing adaptations and innovations in (i) new processes and resources to facilitate disciplinary and interdisciplinary work, and (ii) harmonization and streamlining of patient journeys.
- <u>Biobank and Population Cohort Network (BCNet)</u> National Institutes of Health, CGRF, Project Award 66415; Phase I (01/06/2020–31/12/2022; €74 000) and Phase II (01/01/2023–01/03/2025; €74 000).
  - → The LMICs Biobank and Cohort Building Network (BCNet) initiative arose from the realization that despite improvements in developed countries, population cohorts and biobanking facilities are either underdeveloped or non-existent in LMICs. In this context and in line with IARC's mission to contribute to worldwide cancer research, BCNet was set up as an opportunity for LMICs to work together in a coordinated and effective manner and jointly address the many challenges in biobanking infrastructure and capacity development, including ethical, legal, and social issues (ELSIs).
- Human Exposome Assessment Platform (HEAP), Horizon 2020, EU grant agreement ID: 874662; (01/02/2020 – 31/12/2024; €32 000).
  - → HEAP provides a research resource for the integrated and efficient analysis of the human exposome. One primary outcome of the project is the complete process for obtaining actionable knowledge from established and new international cohorts.
- Providing cutting edge cancer research services across Europe (CANSERV) Horizon Europe; (01/09/2022 – 31/12/2025; €116 000).
  - → The European canSERV project aims to defragment the landscape of European cancer research. canSERV will enable academia and industry access to crosscutting services and support from basic science up to clinical translation to foster personalized medicine for patients with cancer (including support on ELSI services).

#### Resources

The team in charge of managing IARC's biobank and laboratory services is made up of 9 permanent staff members, plus 3 to 5 students each year. These personnel are funded on a mix of RB and EB resources. Permanent staff members are distributed as follows:

- → One general and scientific manager (1 FTE),
- → One secretary (0.5 FTE),
- → One laboratory services manager (1 FTE),
- → One biobank business processes manager (1 FTE),
- → One senior biobank technician (1 FTE),
- → Four biobank technicians, including 3 funded by calls for projects (3 FTE + 0.5 FTE),

To consolidate the team, the manager of the Biobank mentions the necessity to invest in a data analyst/data manager, because the data treatment is currently run within other teams of IARC Branches, especially in the NME Branch.



The LSB unit holds the following grants, and has demonstrated its capacity to produce successful grant applications for international calls:

PROJECT	BUDGET	FUNDER	DURATION	PERIOD
B3Africa	€365 000	EC Horizon 2020	3 years	01/07/2015 – 30/12/2018
ADOPT BBMRI-ERIC	€113 093	EC Horizon 2020	4 years	01/10/2015 – 31/03/2019
ARICE	€146 856	EC REA	3 years	01/09/2020 – 31/08/2023
IMCOCA	€12 000	CLARA	2 years	01/02/2021 – 01/06/2023
BCNet	€73 850	NIH	2 years	01/06/2020 – 31/12/2022
DONEC	€73 850	NIH	2 years	01/01/2023 – 01/03/2025
HEAP	€32 000	EC Horizon 2020	4 years	01/02/2020 – 31/12/2024
CANSERV	€116 400	EC Horizon Europe	3 years	01/09/2022 – 31/12/2025
IHEN	€84750	EC Horizon Europe	3 years	01/12/2023- 30/11/2026
Integrate Large Med Cohorts	€188 075	EC Horizon 2020	3 years	01/01/2024- 31/12/2026
Interceptor	€0 <sup>17</sup>	EC Horizon 2020	2 years	14/11/2022- 13/11/2024

# **Global reach and impact**

# Open access biobank

The mission of IARC includes promoting cancer research internationally. As a publicly funded international organization with a mandate for collaborative research, the principle of access means that samples and data entrusted to the Agency should be put to the best possible scientific use, taking into account the best interest of the participants and for public benefit.

Access to and use of biological samples under the responsibility of IARC are carried out in compliance with the regulations and ethical rules in force, and are governed by the principles presented in the IARC Policy on Access to Human Biological Materials.

Access to the IBB samples follows the below steps:

- Step 1: Requests for accessing IARC biospecimens should be initially directed to the IARC Biobank (ibb@iarc.who.int). The requestor will complete a Project Application form and a Partner Profile form.
- Step 2: After review of the Project Application and Partner Profile, the IBB submits the request to the IARC PI/CU for an initial review of the request for recommendation to the BSC.

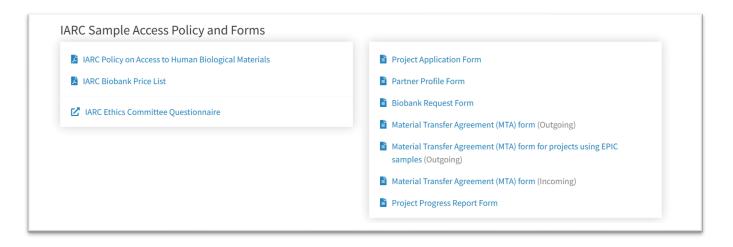
<sup>&</sup>lt;sup>17</sup> There is no budget allocated to IARC or any of the partners. The entire budget is provided only to the coordinator CLB, and its use is limited to supporting travel expenses for the participants in the 4 planned experts' meetings.



- Step 3: Once the request has been approved by the BSC, or the relevant steering committee when applicable, the requestor is informed. The IARC Ethics Questionnaire must then be submitted to the IARC Ethics Committee (IEC) for ethical approval.
- Step 4: Subject to ethical approval by the IEC, a Biobank Request form is prepared together with all required supporting documents; these will enable the IBB to prepare the requested samples and the related MTA.
- **Step 5:** Upon receipt of the signed MTA and payment of relevant sample access charges, the IBB will proceed with shipment of the samples for the project.
- Monitoring and follow-up: In order for the IBB to monitor use of the IARC biological resources, the requestor will be required to submit a Project Progress Report.

Sample applicants contribute to the cost of sample retrieval, pre-analytical processing, and shipping according to the standard costs published on the biobank website (IARC Biobank price list). The IBB is currently introducing the data transfer agreements (DTAs) that come with the MTAs. All forms and reference documents related to access to and use of biological samples are available on the website of the biobank:

- Project Application Form
- Partner Profile Form
- IEC Questionnaire
- Biobank Request Form
- Material Transfer Agreement (MTA)
- Project Progress Report Form

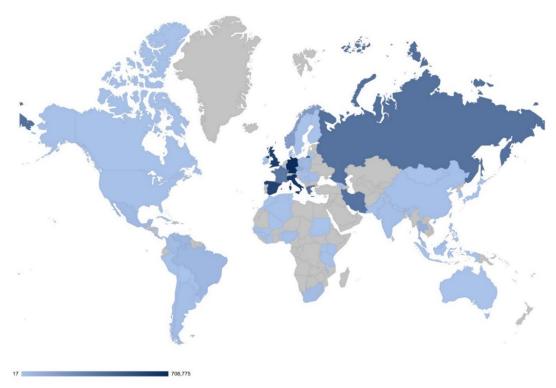


#### Capacity-building in LMICs

The origins of biological samples stored within the biobank are presented on the map below, which shows that it has a real international coverage, including LMICs.

The BCNet programme is mentioned in the MTS 2021–2025 under the title "LMICs Biobank and Cohort Building Network (BCNet)", in the following terms: "IARC created BCNet in 2013 as an opportunity for LMICs to cooperate effectively, and to jointly mobilize knowledge and address challenges in research infrastructure and biobanking. The latter include the collection of biological samples under standardized protocols, and the development of appropriate governance frameworks for biobanking, addressing operational, ethical, legal, and social issues. [...] Beyond providing educational support and a forum for the exchange of experiences and expertise, BCNet facilitates the joint participation of LMIC-based infrastructures in international collaborative research on cancer.





Geographical origin of biological samples kept within the IARC biobank.

IARC will pursue research collaborations involving the LMICs Biobank and Cohort Building Network (BCNet), with an emphasis on web-based components to allow entirely virtual collaborations. Moreover, BCNet members will increasingly use regional groups for peer-to-peer staff exchanges and training, thereby strengthening BCNet's regional impact on capacity building".

As described on its dedicated <u>website</u>, the BCNet capacity-building programme is implemented in collaboration with the Center for Global Health (National Cancer Institute, National Institutes of Health, USA). To date, 54 institutions representing 25 countries are members of the BCNet network, as represented on the map below.



International members of the BCNet network.



As the coordinator of the BCNet network, the IARC Biobank regularly delivers training on biobankrelated activities in different formats (webinars, conferences, on-site training at IARC, on-site training abroad, or remote training). Training on biobanking and infrastructure development has been delivered by BCNet to pathologists, clinical laboratories, medical researchers, and technicians in:

- Yogyakarta and Jakarta, Indonesia (2017, 2018, 2019, 2021, 2024);
- Abidjan, Cote d'Ivoire (2016);
- Eldoret, Kenya (2019, 2020);
- Barretos and São Paulo, Brazil (2019, 2024);
- Cairo and Alexandria, Egypt (2016, 2018, 2019, 2022, 2023, 2024);
- Yerevan, Armenia (2022, 2023);
- Cebu and Manila, Philippines (2023, 2024);
- Kathmandu, Nepal (2024);
- Dakar, Senegal (2023);
- Suzhou, Kunming, and Macao Special Administrative Region, China (2022, 2023, 2024);
- Maputo, Mozambique (2022);
- Lima, Peru (2024);
- Kuala Lumpur, Malaysia (2023, 2024);
- Guatemala City, Guatemala (2022); and
- Dar es Salaam, United Republic of Tanzania (2023).

In addition of BCNet, the personnel of the IARC Biobank are involved in various other training programmes:

The IARC biobank also provides training on Global Laboratory Leadership Programme (GLLP) good laboratory practices. Dr Kozlakidis was one of the key faculty who designed the WHO Global Laboratory Leadership Programme (GLLP; global launch in 2021; first graduates in 2022).



Online training material is available on the <u>IARC Learning platform</u> and accessible globally. This website includes more than 80 individual resources on biobanking and is visited on average by 200 unique visitors per month.



The IARC biobank is also integrated into the faculty in these Master's programmes:

- "Management of biobanks" offered by the Catholic University of Lyon (ESTBB), France;
- the Master's "Biobank and Complex Data Management" offered by the Cote d'Azur University, France:
- the Master's programme "Biobanking and Medical Research" at the Medical Research Institute, University of Alexandria, Egypt;
- the Master's programme "Biobanking" at the Medical University of Graz, Austria;
- the Master's programme in "Health Management", Centre for Health Innovation Research, City University of London, United Kingdom



# Interface with other Pillars and Branches

• The IARC biobank is a shared research infrastructure, which leads to collaboration with nearly all the scientific Branches.

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU: Collaboration on the project Impact of COVID-19 on Cancer (CLARA).	NME: Many collaborations, including for EPIC study.  GEM: Some collaboration for the Mutographs and Discern projects, but with another software.	EGM: A few collaborations on scientific projects on childhood cancer EPR: A few collaborations on scientific projects	LCB: Many collaborations on training session (8 to 10 workshops per year).  ESC: Collaboration with WCT on pathology laboratories.

# **Key Performance Indicators (KPIs)**

The LSB team uses several KPIs to measure and to monitor the activities of the biobank. The objective is to support scientific collaborations as part of the biobank, to support the contribution of this infrastructure in promoting Open Science and avoid being just storage equipment.

The main KPIs are the following:

- number of samples held,
- number of samples used,
- → number of projects using the biobank,
- grants to fund the biobank activities,
- accreditation (attainment and subsequent renewal),
- number of publications.

The biobank team (LSB) has produced more than 80 peer-reviewed scientific publications in the past 5 years (01/01/2018–25/01/2023). Most of these publications are technical, and several are high impact. The 10 most important publications are listed below:

- Kozlakidis, Z., 2023. The incidence of Coronavirus Disease 2019 (COVID-19) among vaccinated healthcare workers (HCWs): Evidence for protection from hospitalisation from an Indonesian cohort. The Lancet Regional Health. Southeast Asia.
- Ngwa, W., Addai, B. W., Adewole, I., Ainsworth, V., Alaro, J., Alatise, O. I., ... and Kerr, D. (2022).
   Cancer in sub-Saharan Africa: a lancet oncology commission. The Lancet Oncology.
- Liu, Ning-Ning, et al. "Multi-kingdom microbiota analyses identify bacterial—fungal interactions and biomarkers of colorectal cancer across cohorts." Nature Microbiology 7.2 (2022): 238-250.
- Al Knawy, Bandar, et al. "Successfully implementing digital health to ensure future global health security during pandemics: A consensus statement." JAMA Network Open 5.2 (2022): e220214e220214.
- He, Yong-Qiao, et al. "A polygenic risk score for nasopharyngeal carcinoma shows potential for risk stratification and personalized screening." Nature Communications 13.1 (2022): 1966.
- Bogaert, Brenda, et al. "Organisation of cancer care in troubling times: a scoping review of expert guidelines and their implementation during the COVID-19 pandemic." Critical Reviews in Oncology/Hematology (2022): 103656.



- Stejskal, Lenka, et al. "An entropic safety catch controls hepatitis C virus entry and antibody resistance." Elife 11 (2022): e71854.
- Vandenberg, Olivier, et al. "Considerations for diagnostic COVID-19 tests." Nature Reviews Microbiology 19.3 (2021): 171-183.
- Vandenberg, Olivier, et al. "Consolidation of clinical microbiology laboratories and introduction of transformative technologies." Clinical microbiology reviews 33.2 (2020): e00057-19.
- Kozlakidis, Zisis, et al. "Global health and data-driven policies for emergency responses to infectious disease outbreaks." The Lancet Global Health 8.11 (2020): e1361-e1363.

# **Alignment with IARC MTS 2021-2025**

# Contribution to IARC's mission

Open science in cancer research: According to the IARC MTS 2021-2025, "Open Access is a cornerstone of Open Science: "Precision research is based on the analysis of well-characterized, research-ready samples combined with data and/or on the biological validation of data-driven observations. The concept of Open Access to scientific resources will extend to IARC's biobank, i.e. its collections of biological samples under a transparent governance and accessibility framework. To ensure the sustainability of the biobank's operations, selected samples may be made available on a cost-recovery basis". "IARC's laboratory platforms and biobanking services:

Laboratory platforms and biobanking services will continue to constitute a crucial part of IARC's overall support matrix for its scientific activities, in close coordination with other support services, and to ensure that laboratories meet necessary standards and enable state-of-the-art laboratory-based research work. IARC's biobank, aligned with the Open Science principle, will continue to be responsible for one of the largest and most varied international collections of clinical samples in the world, with a focus on gene-environment interactions and disease-based collections."

# Achievements of assigned objectives

"IARC biobank aims to provide an open-for collaboration resource, adhering to trusted quality standards and FAIR principles. It serves as a centralized repository for biological samples and associated data, facilitating findability and interoperability, and is dedicated to meeting international accreditation standards".

- The biobank directly contributed to the definition and to the implementation of the IARC Open Science strategy, as shown in the IARC vision for Open Science presented to the Scientific Council in February 2024.
- → As an international agency based on French territory, a first objective of the IARC Biobank was to become compliant with the IBiSA label programme dedicated to French Biological Resources Centres. This objective was reached in 2023. Another great illustration of this Open Science approach is the fact that the IARC Biobank feeds more than 60 international scientific projects per biennium, involving more than 250 partners at the international level.

# Integration in to the IARC Project Tree

The biobank is integrated into the IARC Project Tree under the following objectives:

# Level 2 Objective:

→ Objective 6 "Strengthening the efficiency and effectiveness of the Agency's research and collaboration."

# Level 3 Objective:

→ Objective 6.1 "Ensure the availability of adequate laboratory and computing/statistical infrastructure to support and enhance research."

In addition, the IARC biobank represents a major infrastructure for the **research projects and consortia using biological samples, such as EPIC** (see case study), mainly related to the Level 2 Objective "Understanding the causes of cancer".



# Main challenges and future perspectives

# Challenges

- The IARC Biobank is entering a new era with a state-of-the-art facility in a new building based on Open Science. Therefore, there is a clear need to accelerate the implementation of a new quality management system that will be in line with the ultra-modern building and facilities. New processes will be implemented to respond to the requirements of the new building and its new constraints, and to respond to the new rules and regulations, which are always evolving towards more stringent controls and quality checks.
- Also, the objective of the biobank is to reach centralization of samples and data, in one shared infrastructure. According to the biobank head, this ambition was largely supported by the transfer in 2022 of biological samples to the new biobank in the new IARC premises in Lyon Gerland. About 25% of the samples at the Agency are still managed outside of the biobank, within the scientific Branches, but several of these collections are outdated and with limited data.
- The IARC Biobank now offers extra capacity that IARC is not yet using (up to 10 million samples in total), and its team would like to increase its rate of use. Therefore, the ambition of the biobank is to collaborate more with external partners, such as the contract IARC is running with SomaLogic, a company specialized in next-generation proteomics.
- Finally, the head of the IARC biobank considers that the following challenges should be addressed in the coming years to upgrade the IARC biobank:
  - o Managing the research infrastructure: planning, operating, and evaluating the infrastructure
  - O Definition of all manuals/standard operating procedures for the biobank activities, for example the process in case of a break down.
  - o Monitoring of consumption, repairs, and life expectancy of the equipment,
  - o Monitoring the carbon footprint of the biobank.

#### **Perspectives**

- → The objective for the IBB, and because of its international status, is the ISO 20387 certification by the end of 2026. This standard ISO 20387 "Biotechnology and Biobanking" was developed with the aim of promoting trust in biobanking. It contains requirements aimed at enabling biobanks to demonstrate that they are competent and able to provide biological materials and associated data of appropriate quality for research. The IARC biobank wishes to highlight its competence, impartiality, and the implementation of strong quality control requirements to ensure the appropriate quality of collections of biological materials and associated data distributed for research purposes.
- → In order to obtain the ISO 20387 certification for the IBB in 2026, the following steps are planned in the coming months:
  - → Initial audit of the IBB processes and operations,
  - → Training of the IBB staff on quality management requirements,
  - → Development, set up, and implementation of the IBB quality management system,
  - → Metrology upgrade for IBB equipment,
  - → Internal audits,
  - Certification audit (ISO 20387).
- → An additional future plan is the environmental sustainability of the biobanking operations. The IARC biobank is leading globally in this effort, and a recent publication introduced the subject of decarbonization within the global biobanking community for the first time: Shirakashi, R., Kozlakidis, Z., Yadav, B. K., Ng, W., Fachiroh, J., Vu, H. and Furuta, K. (2022). Decarbonization in Biobanking: A Potential New Scientific Area. Biopreserv Biobank, 20(5), 446-450.

# For more details

- → <u>IARC Biobank</u> <u>website</u>
- → BCNet website
- Biobanking learning platform



# Implementation of the IT roadmap

During the 2021–2025 MTS period, the following key areas of the IT strategy were addressed, according to the Information Technology Services, leading to several significant accomplishments:

- → IT infrastructure transfer: The transfer and implementation of the new IT infrastructure was one of the primary focus areas. The relocation to the new headquarters in Gerland was completed smoothly, with the IT infrastructure fully operational by the end of 2022. Moreover, in 2024, the storage infrastructure and the virtual environment were upgraded to a more modern system.
- → Digital workplace: Another major success was the establishment of a comprehensive digital workplace. IARC now operates in a fully dematerialized environment, enabling seamless remote collaboration across the globe. The deployment of Office 365 services, including Teams, OneDrive, and IP-based phone systems, has been well received. However, the migration of SharePoint to the cloud is still in progress, with varying levels of adoption across different departments.

Two areas of the IT strategy, which were objectives during the current MTS period, require further attention and are included in the recommendations for future improvement:

- → IT security: IARC's cybersecurity resources are currently minimal and are heavily dependent on WHO's initiatives. As an international research organization within the UN system, it is vital for IARC to strengthen its cybersecurity infrastructure, making this a key priority in the next MTS. ITS is currently capitalizing on WHO's existing contract with Kudelski Security, which is scheduled to conclude in the first quarter of 2025. In anticipation of this, WHO is actively seeking comprehensive cybersecurity service alternatives for contract renewal. It will be necessary for IARC to allocate a dedicated staff member to oversee the relationship and associated tasks. An additional area of security to explore is the backup system in collaboration with the WHO Academy.
- → Business Management System (BMS) implementation: The implementation of the BMS was not feasible during the MTS period, primarily due to delays from WHO. IARC aimed to implement the system by January 2024. However, WHO postponed its go-live date of BMS to July 2025, with a request for IARC to delay its implementation by 6–12 months after WHO's system is live. In addition, concerns have been raised regarding the suitability of the system for IARC's specific requirements. In response, IARC has begun exploring alternative solutions, such as Quantum ERP, a flexible cloud-based system developed by UNDP and supported by Oracle cloud services. IARC should be able to make an informed decision in 2025, and initiate implementation in 2026.



# Main conclusions and recommendations: inputs



# **Participating States**

IARC has made significant progress in welcoming new Participating States (PS), adding three between 2021 and 2024. This expansion strengthens the Agency's governance and regular budget. With all countries from Groups 1, 2, and 3 now part of IARC, future recruitment efforts will focus on Groups 4 and 5, which present unique challenges. A shortlist of 14 target countries includes Colombia, Czechia, Greece, Indonesia, Kazakhstan, Kuwait, Luxembourg, Malaysia, Mexico, New Zealand, Poland, Portugal, South Africa, and the United Arab Emirates. To improve attractiveness:

- Allocate additional resources to prioritize this effort.
- → Enhance senior management involvement in the process.
- → Consolidate IARC's network of advocates, and tailor strategies to address the specific needs of prospective PS.

# **Budget and resource mobilization**

The evolution of IARC's Regular Budget (RB) has not kept pace with inflation or annual salary increases, effectively resulting in a shrinking budget. Meanwhile, Voluntary Contributions (VC) have doubled during the MTS period, reaching parity with the RB at approximately €21 million per year. This shift in funding raises key challenges, including aligning scientific priorities with funders' expectations and establishing suitable administrative and HRO processes.

With more than 60 external funders annually, and 77% of VCs concentrated among the top seven funders, IARC is encouraged to:

- → Implement a Key Account Management (KAM) approach to manage major funders more effectively.
- → Adopt Results-Based Budgeting (RBB) to integrate RB and VC, align financial resources with strategic priorities, and support IARC flagship programmes.

# Workforce and gender balance

IARC's workforce is composed of two thirds female and one third male personnel, a ratio that has remained stable during the current MTS. At the management level (Branch Heads and Deputy Branch Heads) and in Research Team leadership, a good gender balance has been achieved. At the executive level (P5 level and above), women make up 30% of personnel, and this proportion is gradually increasing. Notably, as of 2024, IARC's two highest-ranking positions (Director and Director of Administration and Finance) are held by women from LMICs (Brazil and India).

# **Workforce and geographical representation**

To enhance the geographical diversity of its staff and better represent its Participating States, IARC should focus on:

- Encouraging representation from PS In the Middle East, including Egypt, Saudi Arabia, and Qatar.
- Encouraging representation from PS In Asia, including China and Japan.



# **Workforce and diversity**

Several initiatives have emerged during the MTS period to support diversity. The Equity and Diversity Advisory Group (EDAG) has played a pivotal role in supporting the IARC Award for Women in Cancer Research and conducting a Disability Awareness Survey to foster inclusivity. After the move to its new headquarters in 2023, IARC's facilities now fully comply with French accessibility regulations for disabled persons.

IARC is encouraged to:

- Sustain long-term support for diversity initiatives.
- → Actively encourage applications from candidates with disabilities to fulfill the goals of its Diversity, Equity, and Inclusion (DEI) strategy, published in 2022.

#### **Research infrastructure**

The successful relocation to IARC's modern headquarters in Lyon Gerland is a major achievement, providing 11 500 m<sup>2</sup> of state-of-the-art facilities that promote Open Science. To maximize the potential of this new infrastructure, IARC should:

- Implement its eco-friendly action plan in the short term.
- → Strengthen synergies with the WHO Academy and scientific partners in the Lyon-Gerland Biodistrict.

The new biobank, a critical resource with a capacity of up to 10 million biological samples, serves as an international showcase for IARC. To leverage its full potential, IARC is encouraged to:

- Expand collaborations to external partners.
- Strengthen quality management and pursue ISO certification.
- → Extend open science practices and enhance the visibility of other laboratory activities to foster research excellence and strengthen collaborative performance.

The upgraded IT infrastructure has enhanced IARC's digital workplace, storage capacity, and Scientific IT platform. Moving forward, IARC should:

- Strengthen cybersecurity infrastructure to safeguard its data and operations.
- → Select and implement an Enterprise Resource Planning (ERP) solution to improve administrative workflows and support scientific programmes.

# 2. MTS Outputs

→ The second category of KPIs for evaluating the MTS 2021–2025 focuses on outputs, which represent the direct deliverables of the Agency. These outputs encompass scientific publications (2.1), learning events and courses (2.2), training programmes and fellowships (2.3), and the methods and processes involved in the implementation of the MTS (2.4).





# 2.1 Publications

# **Publication outputs**

Main ambitions of the MTS 2021-2025:

- Promotion of scientific excellence in cancer prevention
- Collaborations between disciplines
- Implementation research

## KPIs:

- Reviews of IARC scientific Branches
- Number and evolution of publications
- → H-index overall and per Pillar

Source: SSR (PLW), all Branches

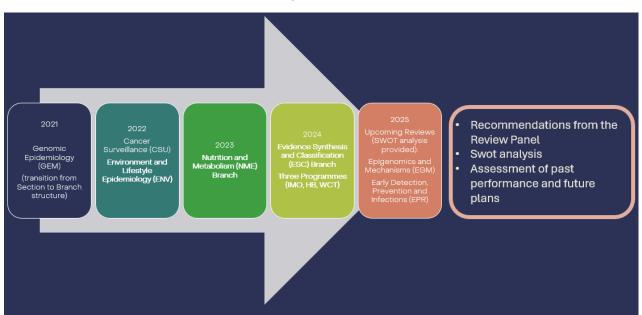
To provide an overview of IARC's scientific production, a summary of the 5-year review of IARC scientific Branches is presented below. A detailed bibliometric study, published for the evaluation of the IARC MTS 2021–2025 and included in the appendices, offers key figures on the Agency's output. In line with the requirements of the MTS evaluation framework, a selection of 5 to 6 major publications per Pillar has also been identified, offering a qualitative perspective on IARC's scientific contributions.

# Overview o reviews of IARC scientific Branches

During the MTS period, four IARC Branches underwent review, as follows:

- 2021: GEM (formerly the Genomic Epidemiology Section), comprising the Genetic Epidemiology Group (GEP) and the Genetic Cancer Susceptibility Group (GCS)
- 2022: CSU

- 2023: NME
- 2024: ESC (includes three Programmes: the IARC Monographs Programme (IMO), the IARC
  Handbooks Programme (IHB) and the WHO Classification of Tumours Programme (WCT);
  the Branch was reviewed in its entirety).



This section outlines the recommendations from the Review Panels. Detailed SWOT analyses for each Branch are included in the appendices for further reference.

# Genomic Epidemiology (GEM) Review (2021)

#### Recommendations from the Review Panel:

- → Continued support of GEM at the highest level for its proposed comprehensive research programme, training, and capacity-building, which is critical for the IARC MTS.
- → Focus research strategy on addressing understudied cancers and populations, particularly in LMICs, with a high priority for research in African populations.



- → Maintaining infrastructure critical to GEM and various other IARC Branches including biobanking, pathology, bioinformatics and novel omics technologies is essential. At the same time, outsourcing other laboratory work, such as large-scale sequencing, should be considered where appropriate.
- → GEM has overlapping interests with other Branches. Less clear was how GEM will strategically interact with other Branches, and where new opportunities might exist.
- → GEM involvement and leadership in the Computational Biology, Bioinformatics and Biostatistics Working Group is seen as critical for future GEM research (as well as IARC overall).
- → The lung cancer work (early detection biomarkers) highlights cross-agency collaborations and may generalize to other early detection work within GEM (oropharyngeal cancer, bladder cancer).
- → Leveraging GEM expertise as part of IARC's education programme should be enhanced.

# Cancer Surveillance (CSU) Branch Review (2022)

#### Recommendations from the Review Panel:

- → CSU is underfunded: ensure secure support (RB funding) for CSU and GICR to maintain IARC's position as a premier provider of global cancer surveillance and descriptive epidemiology research.
- → Strategic positioning relative to other large international descriptive (cancer) epidemiology efforts would be valuable for CSU.
- Direct application to cancer data capture: connect CanReg5 with DHIS2 and other facility-based data platforms.
- → Investigate options that maximize efficiency and collaboration in the development of PAF and other key indicators for cancer prevention.
- → The multi-partner approach to estimating the proportion of cancers attributable to lifestyle and environmental risk factors in France might provide a template for country engagement.
- Cancer inequalities and Health Economics and Cancer need continued attention and support.
- → New areas of research: methods for integration and harmonization of complex diverse data sources; artificial intelligence and machine learning; methods for causal inference; federated data analysis methods or synthetic data methods.
- → Development of tools for the local analysis of our global data resources with national partners.
- Direct assessment of policy uptake (policy impact tools such as Overton).

# Environment and Lifestyle Epidemiology (ENV) Branch Review (2022)

#### Recommendations from the Review Panel:

- → Internal funding from the regular budget be allocated to ENV.
- → To increase the work being initiated and conducted in LMICs and expand it to other countries.
  - New: Oil industry (Nigeria)
  - Consortium of exposures in mining industry in Africa
  - o Occupational cancers in the Islamic Republic of Iran
  - o Improving breast cancer survival two new countries: Ghana, Egypt. One new activity: increasing breast awareness (Ghana, United Republic of Tanzania)
  - o Recent additional activity skin cancer in persons with albinism
  - o Codes against cancer LAC, Asia
- → Include studies of exposures to potentially important new causes of cancer (possibility of developing a priority plan).
  - o Oil industry (Nigeria) with UNEP and STPH
  - o Tattoos (German, France, and USA): 1 P1 scientist, 1 postdoctoral scientist



- → To lead and support dissemination efforts in LMICs and help build up capacity in these countries.
  - o Regional Codes Against Cancer: LAC, Asia next, Future: Africa and Middle East
- → To prolong its policy to focus on areas where ENV can make a difference.
  - o Locations, cancers, exposures that are understudied or challenging to study
  - Nigeria delta region and oil industry; Cancers bladder (Malawi); Skin cancer in persons with albinism
  - Need for an impartial partner: Fukushima, radiation work, oil industry, Asbest cohort, future cohorts in the Russian Federation (coal mining)
  - A need for numbers: consortia leadership childhood cancer (CLIC), AGRICOH/AGRICAN, AfrECC (Oesophageal cancer in Africa)
- → To maintain critical mass in radiation research in Belarus, Ukraine, Kazakhstan, and Japan.
- → To establish a position in exposure assessment, with a focus on LMICs-specific exposure circumstances.

# Nutrition and Metabolism (NME) Branch Review (2023)

#### Recommendations from the Review Panel:

- → Strongly supports NME's exceptional molecular and nutrition epidemiological research integrating metabolomics, proteomics, hormone measurements, and genomics within population studies.
- → To evaluate the long-term sustainability of the in-house metabolomics platform (maintaining vs outsourcing).
- → To maintain and upgrade the research infrastructure for EPIC data as well as sample replenishment for cancer cases where the biosamples have been depleted. Continued collection and centralization of repeated measures of diet and lifestyle factors during the long-term follow-up.
- → To participate or initiate consortia for cancer survivors.
- → To expand studies on multimorbidity by integrating additional existing resources and realworld databases.
- → To carefully evaluate whether conducting lifestyle intervention trials is a high-priority research area for NME/IARC.
- → To integrate the Precision Nutrition framework within NME's ongoing and future projects.
- → To enhance efforts to conduct validation studies of novel dietary indices.
- → To invest in new approaches for the pre-processing and statistical analysis of omics data for their use in cancer studies.
- → To continue/strengthen research in LMICs and contribute to capacity-building in these countries.
- → Support to EB-funded scientists (portion of RB support).

# Evidence Synthesis and Classification (ESC) Branch Review (2024)

#### Recommendations from the Review Panel:

- → Recognize the unique aspects of each programme while continuing to foster synergies among resources, activities, and developments when appropriate.
- → Integrate representatives from LMICs (IARC trainees, Visiting Scientists, Summer School attendees, observers, etc.) and early-career researchers into ESC activities to enhance global inclusion.
- Address concerns regarding short-term contracts for some staff members, exploring potential solutions to improve stability and retention.
- → Maintain and expand efforts towards increased dissemination of ESC outputs. External advice on implementation and scientific communication could help broaden dissemination to policy-makers, stakeholders, the general public, and patient groups, particularly to combat disinformation.



- → Recognize editing as a critical, labour-intensive step in evidence synthesis. Continue exploring ways to streamline and accelerate the editing process.
- → Diversify external funding sources to strengthen the financial foundation of ESC programmes.
- → Maintain ESC's rigorous efforts and strict policies to avoid conflicts of interest, ensuring the integrity and credibility of its outputs and evaluations.

## 2025

Two Branches will be reviewed in 2025: the **Epigenomics and Mechanisms (EGM) Branch** and the **Early Detection, Prevention and Infections (EPR) Branch**. The SWOT analyses for the two Branches are provided in the appendices.

# Evolution of IARC's scientific publications and bibliometric analysis

A bibliometric study was published for the evaluation of the IARC MTS 2021–2025 (appendices). It focuses on the scientific production of IARC from January 2021 until May 2024, to provide a synthesized overview of IARC's publications during the MTS period and some comparison with the previous MTS 2016–2020. The elements were discussed with the IARC Senior Advisory Team on Management (SAT) during an SAT meeting on 6 June 2024 and with the management of the Agency for the MTS retreat on 4 September 2024. The key elements of this bibliometric study corresponding to the MTS evaluation framework are presented below; the detailed bibliometric study is in the appendices.

Table 13 presents the evolution of IARC's publications since 2016, with the proportion of peer-reviewed articles per year. After a regular increase during the previous MTS 2016–2020, the annual number of publications has been decreasing since the 2020 record of 470 publications but has remained higher than during the previous MTS period. This downward trend aligns with global publication patterns observed by Clarivate Analytics<sup>18</sup>. Notably, the proportion of peer-reviewed articles has remained consistently high and stable, ranging from 78% to 82% throughout the MTS 2021–2025 period.

Table 13. Evolution of IARC's publications since 2016 <sup>19</sup>						
MTS	Year	Articles	Peer-reviewed articles	% of peer-reviewed articles		
	2016	341	290	85%		
1470	2017	352	291	83%		
MTS 2016-2020	2018	351	284	81%		
2010 2020	2019	371	292	78%		
	2020	470	387	82%		
	2021	438	361	82%		
MTS 2021-2025	2022 2023	440 386	341 303	78% 78%		
	Apr 2024	101	83	82%		

# Scientific productivity of IARC's scientists

In line with the MTS evaluation framework, the number and evolution of publications per scientific staff (P-staff) and Early Career and Visiting Scientist (ECVS) provide insights into the scientific productivity of IARC (Table 14). Table 14 presents the productivity data of IARC's scientific

<sup>19</sup> Source: IARC PLW, May 2024

<sup>&</sup>lt;sup>18</sup> 2024 Clarivate Analytics Journal Citation Reports.



personnel from January 2021 to April 2024. On average 1.85 publications were published per year for each IARC personnel member (P-staff and ECVS) during the first 3 years of the MTS period. This ratio goes up to 4.58 publications per year for each P-staff. Restricting to scientific P-staff, the average number of publications reaches 6 publications per year for each P-staff in the Branches. These ratios reflect an improvement in scientific productivity compared with the previous MTS period, demonstrating progress in the output of IARC's personnel. The year 2024 is excluded from this analysis, because complete publication data for the year are not yet available.

	Table 14. Number of publications for IARC scientific personnel <sup>20</sup>							
мтѕ	Year	Publica- tions	P- staff	Number of publications per P-staff	ECVS	Number of publications per ECVS	Total scientific staff	Number of publications per scientific staff (P-staff and ECVS)
	2016	341	103	3.31	99	3.44	202	1.68
	2017	352	106	3.32	104	3.38	210	1.67
MTS 2016-	2018	351	102	3.44	118	2.97	220	1.59
2020	2019	371	106	3.50	109	3.40	215	1.72
	2020	470	103	4.56	126	3.73	229	2.05
	2021	438	99	4.42	115	3.81	214	2.05
MTS	2022	440	87	5.06	147	2.99	234	1.88
2021- 2025	2023	386	90	4.29	132	2.92	222	1.74
_3_0	April 24	101	98	-	145	-	243	-

Table 15 highlights the scientific productivity within IARC Branches for the period January 2021 to April 2024, showcasing the ratio of publications to the average number of scientific personnel (P-staff and ECVS) per Branch during this timeframe. The three most productive Branches in terms of publications per personnel member are NME, CSU and GEM. Across the Agency, the average productivity per scientific staff member was 6.5 publications during the evaluated period.

Table 15. Number of publications according to the type of personnel <sup>21</sup>							
Branch	Publications January 2021 - April 2024	Number of P- staff (PI)	Articles per P-staff	Number of ECVS	Articles per ECVS	Total personnel (P-staff and ECVS)	Articles per scientific personnel
CSU	218	9.5	22.9	17.5	12.5	27.0	8.1
GEM	234	12.0	19.5	18.5	12.6	30.5	7.7
NME	407	12.0	33.9	33.3	12.2	45.3	9.0
ENV	148	7.3	20.3	17.0	8.7	24.3	6.1
EGM	80	5.8	13.8	13.0	6.2	18.8	4.3
EPR	229	13.5	17.0	23.8	9.6	37.3	6.1
ESC	106	11.3	9.4	7.8	13.6	19.1	5.5
IARC	1324	71.4	18.5	130.9	10.1	202.3	6.5

<sup>20</sup> Source: IARC-PLW, HRO and LCB, Web of Science™, April 2024 21 Source: IARC-PLW, HRO and LCB, Web of Science™, May 2024



# Impact of IARC's scientific publications

The h-index is a Key Performance Indicator (KPI) requested by the IARC governance to measure the citation impact of publications by a scientist or a group of scientists (referred to as the corporate h-index). It is defined as the number of publications with citation counts ≥h. For example, an h-index of 17 indicates that at least 17 publications have been cited at least 17 times each. As a signatory of the San Francisco Declaration on Research Assessment (DORA), IARC recognizes both the benefits and the limitations of the h-index. Although it provides a useful quantitative measure of citation impact, it does not account for nuances such as collaboration scope or societal impact. To address these limitations, IARC complements the h-index with other metrics, including the Relative Citation Ratio (RCR) and qualitative indicators such as case studies and a selection of key publications. These additional metrics provide a more comprehensive perspective on the Agency's contributions to the implementation of the MTS 2021–2025. Table 16 provides the corporate h-index of IARC for the current and previous MTS periods, offering a measure of the citation impact of the Agency's scientific output. For the period January 2021 to April 2024, IARC's corporate h-index is 63, based on 1365 publications. Given that the h-index is cumulative, it naturally reflects higher values for older MTS periods, which allow more time for citations to accumulate. Therefore, although the h-index is a valuable KPI for internal or external benchmarking, it is less suitable for historical comparisons within the same organization.

Table 16. Corporate h-index of IARC for current and previous MTS periods <sup>22</sup>						
Period	Total number of publications	Corporate h-Index				
MTS 2005-2009 (5 years)	1 487	173				
MTS 2010-2015 (6 years)	2 037	170				
MTS 2016-2020 (5 years)	1930	146				
Current MTS 2021-2025 (3.33 years)	1365	63				

Table 17 presents the distribution of IARC publications and the h-index per Branch, for the 2021–April 2024 period (definition of h-index in 2.1). CSU is the Branch with the highest cumulative h-index, at 36 for the observed period and a total of 218 publications, followed by NME with an h-index of 30 and a total of 407 publications.

Table 17. Scientific publications and h-index by Branch, 2021 to April 2024 <sup>23</sup>						
Pillar	Branches	Number of publications	h-Index			
Pillar 1	CSU	218	36			
	GEM	234	24			
Pillar 2	NME	407	30			
1 11101 2	LSB	52	11			
	ENV	148	16			
Pillar 3	EGM	80	12			
· ·········	EPR	229	24			
Pillar 4	ESC	106	20			
Total	IARC	1324	62			

<sup>22</sup> Source: IARC PLW, May 2024

23 Source: Ibid.



Table 18 presents the distribution of IARC publications and the h-index per Pillar, for the 2021–April 2024 period. Pillars 1 and 2 have the highest h-index.

Table 18. Scientific publications and h-index by Pillar, 2021 to April 2024 <sup>24</sup>						
Pillar	Number of publications	h-index for period				
Pillar 1	218	36				
Pillar 2	653	38				
Pillar 3	440	28				
Pillar 4	106	20				
Total	1324	62				

In addition to the h-index, it is worth mentioning the scientific influence of IARC publications for 2021–May 2024 based on the RCR. The RCR measures the scientific influence of each paper by field- and time-adjusting the citations it has received, and benchmarking to the median for NIH publications. This indicator shows that the 1341 publications of IARC for 2021–May 2024 are cited on average 12.39 times more than similar articles in the same field for the same period. Table 19 below presents the distribution of IARC publications and the RCR index per Branch, for the 2021–May 2024 period (definition of RCR in 2.1). CSU is the Branch with the highest RCR, indicating that CSU publications are cited 52.38 times more on average than publications from other organizations in the same field. Similarly, ESC publications are cited 12.05 times more.

Table 19. Scientific publications and RCR index by Branch, 2021 to May 2024							
Pillar	Branch	Number of publications	RCR index				
Pillar 1	CSU	222	52.38				
	GEM	241	3.77				
Pillar 2	NME	408	3.67				
	LSB	51	3.18				
	ENV	147	1.95				
Pillar 3	EGM	82	1.5				
	EPR	236	3.2				
Pillar 4	ESC	107	12.05				
Total	IARC	1 341	12.39				

Table 20 presents the distribution of IARC publications and the RCR index per Pillar, for the current MTS period. As observed above, Pillars 1 and 4 have the highest RCR index for the observed period, with an RCR of 52.38 and a total of 222 publications for Pillar 1, followed by a RCR of 12.05 and a total of 107 publications for Pillar 4.



Table 20. Scientific publications and RCR index by Pillar, 2021 to May 2024<sup>25</sup>

Pillar	Number of publications	RCR-index
Pillar 1	222	52.38
Pillar 2	659	3.41
Pillar 3	447	2.57
Pillar 4	107	12.05
Total	1341	12.39

### Benchmarking the impact of IARC's publications

The following table<sup>26</sup> compares IARC's publication impact from 2021 to October 2024 with that of prominent cancer research institutions across France, Europe, the USA, and other countries. Key metrics include the number of publications, total citations, average citations per publication, and the corporate h-index, providing insight into the reach and influence of each institution's research output.

Although IARC's publication volume is modest due to its smaller size compared with other leading cancer institutions, it is substantial relative to its capacity. Notably, IARC's citations-perpublication ratio is 2-6-fold higher than other leading institutions in oncology, underscoring the high impact and relevance of its research. In addition, IARC's corporate h-index is relatively high, highlighting IARC's role as a major contributor to impactful cancer research.

<sup>25</sup> Source: IARC PLW, June 2024. <sup>26</sup> Source: Web of Science, Nov. 2024. Only publications categorized under "Oncology" in Web of Science were included in this



		Publications for IARC (2021-October 2024)				
Benchmarks	Institutions	Number of publications	Number of citations	Average citations per publications	Corporate h-index	
	IARC/WHO (Lyon, France)	1219	73 610	60.39	59	
	CLB - CRCL (Lyon, France)	1032	15 431	14.95	52	
France	Institut Curie (Paris, France)	1191	14 600	12.26	51	
	Institut Gustave Roussy (Paris Villejuif, France)	1833	35 942	19.23	83	
	Trinity College (Dublin, Ireland)	307	5003	16.30	28	
	Imperial College (London, UK)	944	15 628	16.56	50	
Europe	Erasmus MC (Rotterdam, Netherlands)	1784	24 662	13.82	62	
	Karolinska Institutet (Stockholm, Sweden)	1751	19 960	11.40	57	
	Stanford Cancer Institute (Palo Alto, USA)	423	13 900	32.86	54	
	Fred Hutchinson Cancer Center (Seattle, USA)	1391	27 391	19.69	73	
USA	St. Jude Children's Research Hospital (Memphis, USA)	993	12 666	12.76	52	
	Moffitt Cancer Center (Tampa, USA)	1613	31 362	19.44	76	
	Mayo Clinic (USA)	3134	43 993	14.04	83	
	Harvard (Cambridge, Boston, USA)	7055	111 751	15.84	130	
	MD Anderson (Houston, USA)	5068	81 384	16.06	119	
	MC Gill University (Montreal, Canada)	939	10 425	11.10	47	
Other	University of Toronto (Toronto, Canada)	3306	40 005	12.10	81	
countries	Fudan University (Shanghai, China)	3814	36 960	9.69	68	
	University of Sydney (Sydney, Australia)	1428	19 916	13.95	59	



### The selection of the most relevant publications per Pillar

A selection of major publications per Pillar were defined by the Pillars coordinators of IARC and discussed during the MTS seminar 05 September 2024. This selection of 5 or 6 publications per Pillar is presented below. The detailed presentations of those publications are available in the bibliometric analysis, including comments on their scientific, public health, and societal impacts, as well as Contribution to the MTS implementation.

Pillar 1 – Data for action

1

### Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries

Authors: Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, Jemal A References: CA: A Cancer Journal for Clinicians; Volume: 74, Issue: 3, Pages: 229–263; April 4, 2024

→ This publication presents global cancer statistics for 2022, emphasizing geographic variability across 20 world regions in the 10 leading cancer types. It discusses recent trends and underlying determinants, highlighting the importance of investments in prevention: "the targeting of key risk factors for cancer (including smoking, overweight and obesity, and infection), could avert millions of future cancer diagnoses and save many lives worldwide, bringing huge economic as well as societal dividends to countries over the forthcoming decades."

2

### <u>Cancer survival in Africa, central and south America, and Asia (SURVCAN-3):</u> <a href="mailto:approximation-based-benchmarking-study-in-32-countries">a population-based benchmarking study in 32 countries</a>

Authors: Soerjomataram I, Cabasag C, Bardot A, Fidler-Benaoudia MM, Miranda-Filho A, Ferlay J, Parkin DM, Ranganathan R, Piñeros M, Znaor A, Mery L, Joko-Fru YW, Dikshit R, Sankaranarayanan R, Swaminathan R, Bray F; SURVCAN-3 collaborators

References: Lancet Oncology; Volume: 24, Issue: 1, Pages 22-32; January 24, 2023

- → Cancer survival is a key measure of overall effectiveness of the health system in delivering cancer care, however availability and quality of the statistics remains limited in transitioning countries. SURVCAN-3 analyses net survival for 15 cancer types using data from 68 registries and identifies three groups based on outcomes and Human Development Index (HDI):
  - o Low survival (<30%): Cancers like lung and stomach, with minimal HDI variation.
  - o Intermediate survival (30-79%): Cancers such as cervix and colorectum, showing moderate HDI variation.
  - o High survival (≥80%): Cancers like breast and prostate, exhibiting substantial HDI variation.





### Global Stage Distribution of Breast Cancer at Diagnosis: A Systematic Review and Meta Analysis

Authors: Benitez Fuentes JD, Morgan E, de Luna Aguilar A, Mafra A, Shah R, Giusti F, Vignat J, Znaor A, Musetti C, Yip CH, Van Eycken L, Jedy-Agba E, Piñeros M, Soerjomataram I References: JAMA Oncology; Volume:10, Issue: 1, Pages: 7-15; 2024

→ Stage is an important indicator for awareness to breast cancer, effectiveness of early detection and screening programmes. This systematic review and meta-analysis examine the global distribution of breast cancer stage at diagnosis, utilizing registry data from 81 countries. The study highlights significant disparities, with the proportion of cases presenting with distant metastatic breast cancer being particularly high in sub-Saharan Africa (5.6% to 30.6%) compared to North America (0.0% to 6.0%). In high income countries with historical data, a decrease or stabilization in distant metastatic diagnoses was observed. Key factors influencing these trends included older age and lower socioeconomic status.

4

### Quantitative estimates of preventable and treatable deaths from 36 cancers worldwide: a population-based study

Authors: Frick C, Rumgay H, Vignat J, Ginsburg O, Nolte E, Bray F, Soerjomataram I References: The Lancet Global Health; Volume: 11, Issue: 10, Pages: e1444-e1454; September 26, 2023

→ Cancer is a leading cause of premature mortality worldwide. This study estimates premature deaths among individuals aged 30–69 years, distinguishing between deaths that are preventable (via primary or secondary prevention) and those that are treatable (via curative treatment). In 2020, there were 182.8 million years of life lost (YLLs) due to premature cancer deaths, with 124.3 million (68.0%) classified as preventable and 58.5 million (32.0%) as treatable. Lung cancer accounted for the largest proportion of preventable premature YLLs in medium to very high HDI countries (17.4% of all cancers), while cervical cancer was the leading cause in low HDI countries (26.3% of all preventable cancers). Colorectal and breast cancers emerged as significant treatable cancers across all HDI tiers (25.5% of all treatable cancers combined).

5

### Global burden of cancer in 2020 attributable to alcohol consumption: a population-based study

Authors: Rumgay H, Shield K, Charvat H, Ferrari P, Sornpaisarn B, Obot I, Islami F, Lemmens VEPP, Rehm J, Soerjomataram I

References: The Lancet Oncology; Volume: 22, Issue: 8, Pages: 1071-1080; August 2021

→ Alcohol use is causally linked to multiple cancers. This study quantifies the proportion of cancer cases attributable to alcohol consumption, revealing that approximately 741,300 cancers (4.1% of all cancers) were linked to alcohol use. Oesophageal, liver and breast cancers are the most significant contributors, with the highest burden observed in Eastern Asia and Central and Eastern Europe. Notably, while heavy drinking accounted for a considerable portion of new cancer cases, moderate drinking also contributed significantly.



### Pillar 2 – Understanding the causes of cancer

1

### Lifestyle changes in middle age and risk of cancer: evidence from EPIC

Authors: P Ferrari, H Freisling, I Huybrechts, K Matta, E Weiderpass References: European Journal of Epidemiology; Volume: 39, Pages: 147–159; January 5, 2024

→ This study evaluates the impact of changing lifestyle habits on cancer risk by comparing lifestyle assessments at baseline and during follow-up. A Healthy Lifestyle Index (HLI) score was calculated based on factors such as cigarette smoking, alcohol consumption, body mass index and physical activity. Among participants in the top third of the HLI at baseline (considered healthy), those who fell to the bottom third at follow-up (considered unhealthy) had a 21% higher risk of lifestyle-related cancers (HR 1.21; 95%CI 1.07–1.37) compared to those who remained in the top third. Conversely, among participants considered unhealthy at baseline, those who improved to the top third at follow-up had a 25% lower risk of lifestyle-related cancers compared to those who remained in the bottom third.

2

### Consumption of ultra-processed foods and risk of multimorbidity of cancer and cardiometabolic diseases: a multinational cohort study

Authors: H Freisling, I Huybrechts, V Viallon, P Ferrari References: Lancet Regional Health Europe; Volume: 14, Issue: 35; November 2023;

→ This study investigates the relationship between total and subgroup consumption of ultra-processed foods (UPFs) and the risk of multimorbidity, defined as the co-occurrence of at least two chronic diseases, including cancer at any site, cardiovascular disease, and type 2 diabetes. The results indicate that higher UPF consumption (excluding alcoholic beverages) is associated with an increased risk of multimorbidity related to cancer and cardiometabolic diseases (HR: 1.09, 95% CI: 1.05, 1.12). These findings suggest that a greater intake of UPFs may increase the risk of developing multimorbidity involving cancer and cardiometabolic conditions.

3

### Circulating inflammatory and immune response proteins and endometrial cancer risk: a nested case-control study and Mendelian randomization analyses

Authors: S Wang, V Viallon, M Lee, N Dimou, C Biessy, ..., S Rinaldi, M Gunter, L Dossus References: Ebio Medicine; In press

→ This study explores the role of inflammation and immune dysregulation in endometrial carcinogenesis by measuring 152 plasma protein biomarkers pre-diagnostically in 624 endometrial cancer case-control pairs nested within the European Prospective Investigation into Cancer and Nutrition (EPIC) cohort. Selected proteins associated with endometrial cancer risk were further analysed in a two-sample Mendelian randomization (MR) using data from the UK Biobank (n=52,363) and the Endometrial Cancer Association Consortium (12,270 cases and 46,126 controls). In EPIC, IL-6 [OR=1.28 (95% CI: 1.03–1.57)], HGF [1.48 (1.06–2.07)] were positively associated with endometrial cancer risk, while HSD11B1 [0.67 (0.49–0.91)], SCF [0.68 (0.49–0.94)], and CCL25 [0.80 (0.65–0.99)] showed inverse associations. MR analysis indicated IL-6 [OR=1.19 (95% CI 1.04–1.36)] and HSD11B1 [0.91 (0.84–0.99)] as associated with endometrial cancer risk.





### Geographic variation of mutagenic exposures in kidney cancer genomes

Authors: Senkin S, Moody S, de Carvalho A, Perdomo S, Alexandrov LB, Stratton MR, Brennan P References: Nature; Volume: 629 - Pages: 910-918; May 23, 2024

→ While smoking, obesity and hypertension are known causes of renal cancer, they do not explain the geographical variation in incidence rates. This study analysed DNA mutations in tumour samples (mutational signatures) from 962 renal cancer cases across 11 countries to identify potential unknown causes of the disease. The somatic mutation profiles varied between countries. Notably, the mutational signatures associated with aristolochic acid compounds were prevalent in Romania, Serbia and Thailand, while rare in other regions. In Japan more than 70% of cases exhibited a mutational signature of unknown origin compared to less than 2% in other countries. Additionally, a common mutational signature of unknown origin was found to have higher mutation loads in countries with higher kidney cancer incidence rates.

5

#### Blood proteome of imminent lung cancer diagnosis

Authors: The Lung Cancer Cohort Consortium, Lead team (GEM): Johansson M, Robbins H, Zahed H. Alcala K

References: Nature Communications; Volume: 24 – Article number: 3726; June 1, 2023

→ Identification of risk biomarkers may enhance early detection of smoking-related lung cancer. Within the framework of the US NCI-funded INTEGRAL project, the researchers measured between 392 and 1,162 proteins in blood samples taken up to three years prior to diagnosis from 731 smoking-matched case-control sets nested within six prospective cohorts from the US, Europe, Singapore, and Australia. The study identifies 36 proteins with independently reproducible associations with risk of imminent lung cancer diagnosis (all p<0.0005).



Geographic and age-related variations in mutational processes in colorectal cancer
Authors: Díaz-Gay M, dos Santos W, (..), Perdomo S, Stratton MR, Brennan P, Alexandrov LB
References: Nature, Under review

→ This study represents the third major publication from the Mutographs project, focusing on the sequencing of 981 colorectal cancer genomes from 11 countries. The analysis revealed multiple signatures, most of which have unknown aetiologies, with varying prevalence in Argentina, Brazil, Colombia, Russia, and Thailand. This suggests geographically diverse levels of mutagenic exposure. Notably, signatures SBS88 and ID18, caused by the bacteria-produced mutagen colibactin, displayed higher mutation loads in countries with higher colorectal cancer incidence rates. SBS88 and ID18 were also enriched in early-onset colorectal cancers, being 3.3 times more common in individuals diagnosed before age 40 than in those over 70 and were established early in colorectal cancer development.

### Pillar 3 – From understanding to prevention

1

### <u>Cancer Mortality in chrysotile miners and millers, Russian Federation: main results (Asbest Chrysotile Cohort Study)</u>

Authors: Schüz J, Kovalevskiy E, Olsson A, Moissonnier M, Ostroumova E, Ferro G, Feletto E, Schonfeld SJ, Byrnes G, Tskhomariia I, Straif K, Morozova T, Kromhout H, Bukhtiyarov I References: JNCI; Volume: 116, Issue: 6, Pages: 866–875, June 2024

→ This study investigates the relationship between chrysotile asbestos exposure and cancer mortality among miners and millers in the Russian Federation. The findings reveal an exposure-response between cumulative dust and lung cancer mortality in men. While no clear association with dust exposure was identified in women, a modest increase in lung cancer risk was observed in the highest category of fiber exposure. Mesothelioma mortality was increased (RR = 7.64, 95% CI = 1.18 to 49.5, to at least 80 fibers per cm3 years and RR = 4.56, 95% CI = 0.94 to 22.1, to at least 150 mg per m3 years (based on 13 deaths). For colorectal and stomach cancer, associations were inconsistent, and no associations were found for laryngeal or ovarian cancer.

2

## <u>Treatment guideline concordance, initiation, and abandonment in patients with non-metastatic breast cancer from the African Breast Cancer-Disparities in Outcomes (ABC-DO) cohort in sub-Saharan Africa: a prospective cohort study</u>

Authors: Foerster M, McCormack V, Anderson BO, Boucheron P, Zietsman A, Cubasch H, Joffe M, Anele A, Offiah S, Galukande M, Parham G, Pinder LF, Ginsburg O, Schüz J, Dos-Santos-Silva I, Kantelhardt EJ

References: Lancet Oncology; May 9, 2022

→ In this study, 68% of participants with non-metastatic breast cancer underwent surgery. Among women with localized tumors, 36% initiated surgery and systemic therapy (i.e., multimodality treatment) with radiotherapy, compared to 23% of those with locally advanced tumours. Furthermore, multimodality treatment without radiotherapy was initiated in 386 (38%) women with localized tumours versus 167 (24%) with locally advanced tumours.

3

### A portable thermal ablation device for cervical cancer prevention in a screen-and-treat setting: a randomized, noninferiority trial

Authors: Basu P, Mwanahamuntu M, Pinder LF, Muwonge R, Lucas E, Nyambe N, Chisele S, Shibemba AL, Sauvaget C, Sankaranarayanan R, Prendiville W, Parham GP References: Nature Medicine; Epub ahead of print on 25 June 2024

→ This RCT aims to demonstrate the noninferiority efficacy of a battery-driven thermal ablation (TA) device compared to cryotherapy and electrosurgical excision (LLETZ) to treat cervical precancer in Zambia. A total of 3,124 women who were tested positive on VIA and were eligible for ablative therapy were randomized to one of the treatment arms. After a median follow-up of 12 months, the treatment success rates were 74.0% for the TA group, 71.1% for the cryotherapy group, and 71.4% for the LLETZ group.





### CanScreen5, a global repository for breast, cervical and colorectal cancer screening programmes

Authors: Zhang L, Mosquera I, Lucas E, Rol ML, Carvalho AL, Basu P; CanScreen5 References: Nature Medicine; Volume: 29, Pages:1135-1145; April 27, 2023

> The CanScreen5 project is a global cancer screening data repository designed to report the status and performance of cancer screening programmes using a harmonized set of criteria and indicators. Data collected mainly from the Ministry of Health in each participating country underwent quality validation and ultimately became publicly available through a web-based portal. As of September 2022, 84 countries reported data for breast (n = 57), cervical (n = 75) or colorectal (n = 51) cancer screening programmes. The findings revealed substantial heterogeneity in program organization and performance, with reported screening coverage ranged from 1.7% in Bangladesh to 85.5% in England for breast cancer, 2.1% in Côte d'Ivoire to 86.3% in Sweden for cervical cancer, and 0.6% in Hungary to 64.5% in the Netherlands for colorectal cancer screening.

### Genome-wide DNA methylation profiling of oesophageal squamous cell carcinoma from global high incidence regions identifies crucial genes and potential cancer markers

Authors: Talukdar FR, Soares Lima SC, Khoueiry R, Laskar RS, Cuenin C, Sorroche BP, Boisson AC, Abedi-Ardekani B, Carreira C, Menya D, Dzamalala C, Assefa M, Aseffa A, Miranda-Gonçalves V, Jeronimo C, Henrique R, Shakeri R, Malekzadeh R, Gasmelseed N, Ellaithi M, Gangane N, Middleton D, Le Calvez-Kelm F, Ghantous A, Roux ML, Schüz J, McCormack V, Parker MI, Ribeiro Pinto LF. Hercea Z.

References: Cancer Research; Volume:81, Pages:2612-2624; May 15, 2021

→ This publication led by EGM, in collaboration with IARC and international partners, identifies new epigenetic changes that are specific to oesophageal cancers in high incidence populations (including LMICs). The study represents the largest genome-wide DNA methylation analysis of its kind, examining aberrant epigenome profiles in ESCC samples from nine countries with high disease incidence across Africa, Asia, and South America. The findings demonstrate that alterations in specific genes can identify tumours with high sensitivity and specificity, suggesting potential use as cancer markers for novel prevention strategies in resource-limited settings.



### Cutaneous and acral melanoma cross-OMICs reveals prognostic cancer drivers associated with pathobiology and ultraviolet exposure

Authors: Vicente ALSA, Novoloaca A, Cahais V, Awada Z, Cuenin C, Spitz N, Carvalho AL, Evangelista AF, Crovador CS, Reis RMR, Herceg Z, Vazquez V de L, Ghantous A References: Nature Communications;

Volume: 13, Article number: 4115; July 15, 2022

→ This study integrates clinical and epigenome (DNA methylome), genome and transcriptome profiling of cutaneous melanoma samples from multi-ethnic cohorts. It identifies UV-related alterations in immunological pathways, with multi-OMICs cancer driver that may impact patient survival. Notably, the research reveals important features of melanomas that are not associated with UV exposure. A subset of cutaneous melanomas lacked UV mutational signatures, displaying a distinct molecular landscape and clinical prognosis different from those of UV-



exposed melanomas but that resembled those of the pathologically distinct acral melanoma. This biological distinction is supported by multi-omics markers of UV exposure critical to immune function. By including patients with varying skin colours, the study enhances the understanding of melanoma origins that may not be triggered by UV exposure, revealing translationally impactful mechanisms in melanoma genesis. The findings promote improvements in conventional protocols for diagnosing, treating, and preventing melanomas.

### Pillar 4 - Knowledge mobilization

1

### Carcinogenicity of occupational exposure as a firefighter

Authors: Demers PA, DeMarini DM, Fent KW, Glass DC, Hansen J, Adetona O, Andersen MH, Freeman LEB, Caban-Martinez AJ, Daniels RD, Driscoll TR, Goodrich JM, Graber JM, Kirkham TL, Kjaerheim K, Kriebel D, Long AS, Main LC, Oliveira M, Peters S, Teras LR, Watkins ER, Burgess JL, Stec AA, White PA, DeBono NL, Benbrahim-Tallaa L, de Conti A, El Ghissassi F, Grosse Y, Stayner LT, Suonio E, Viegas S, Wedekind R, Boucheron P, Hosseini B, Kim J, Zahed H, Mattock H, Madia F, Schubauer-Berigan MK.

References: The Lancet Oncology; Volume: 23, Issues: 8, Pages: 985-6, June 30, 2022

→ This publication evaluates the carcinogenic hazard evaluation of firefighting exposure. Firefighting was classified in Group 1, with sufficient evidence for mesothelioma and bladder cancer, and limited evidence for cancers of colon, prostate, testis, NHL, and skin melanoma in humans. Additionally, the article presents strong mechanistic evidence in humans for five key characteristics of carcinogens: genotoxicity, epigenetic alterations, oxidative stress, chronic inflammation, and modulation of receptor-mediated effects.

2

### Carcinogenicity of perfluorooctanoic acid and perfluorooctanesulfonic acid

Authors: Zahm S, Bonde JP, Chiu WA, Hoppin J, Kanno J, Abdallah M, Blystone CR, Calkins MM, Dong GH, Dorman DC, Fry R, Guo H, Haug LS, Hofmann JN, Iwasaki M, Machala M, Mancini FR, Maria-Engler SS, Møller P, Ng JC, Pallardy M, Post GB, Salihovic S, Schlezinger J, Soshilov A, Steenland K, Steffensen IL, Tryndyak V, White A, Woskie S, Fletcher T, Ahmadi A, Ahmadi N, Benbrahim-Tallaa L, Bijoux W, Chittiboyina S, de Conti A, Facchin C, Madia F, Mattock H, Merdas M, Pasqual E, Suonio E, Viegas S, Zupunski L, Wedekind R, Schubauer-Berigan MK References: The Lancet Oncology; Volume: 25, Issues: 1, Pages: 16-17, November 30, 2023

→ This publication evaluates the carcinogenic hazards of perfluorooctanoic acid (PFOA) and perfluorooctanesulfonic acid (PFOS). PFOA was classified in Group 1, based on sufficient evidence of cancer in experimental animals and strong mechanistic evidence, including epigenetic alterations and immunosuppression in exposed humans. There was also limited evidence for cancers of testis and kidney (renal cell carcinoma) in humans. In contrast, PFOS was classified in Group 2B based on strong mechanistic evidence, including in exposed humans.

3

#### WHO Classification of Tumours. Paediatric tumours

Authors: WHO Classification of Tumours Editorial Board References: WHO Classification of Tumours Editorial Board. Paediatric tumours; WHO classification of tumours series, 5th edition; Volume: 7, 2023



→ This new volume in the 5th series was implemented to support the WHO's global initiative of combating Childhood cancer by supporting correct diagnosis, thereby promoting correct patient management, prognosis and further research.

4

#### WHO Classification of Tumours. Haematolymphoid tumours

Authors: WHO Classification of Tumours Editorial Board
References: WHO Classification of Tumours Editorial Board. Haematolymphoid tumours; WHO classification of tumours series, 5th edition; Volume: 10; 2024

→ This a volume in the 5th series which is highly regarded not only by Pathologists and haematologists but by clinicians and oncologists as well. This publication promotes correct management of patients affected by haematological malignancies, impacts their prognosis and initiates further research especially molecular based research in the current era.

5

### The IARC Perspective on Cervical Cancer Screening

Authors: Bouvard V, Wentzensen N, Mackie A, Berkhof J, Brotherton J, Giorgi Rossi P, Kupets R, Smith R, Arrossi S, Bendahhou K, Canfell K, Chirenje ZM, Chung MH, del Pino M, de Sanjosé S, Elfström M, Franco EL, Hamashima C, Hamers FF, Herrington CS, Murillo R, Sangrajrang S, Sankaranarayanan R, Saraiya M, Schiffman M, Zhao F, Arbyn M, Prendiville W, Indave Ruiz BI, Mosquera Metcalfe I, Lauby Secretan B.

References: New England Journal of Medicine (NEJM); Volume: 385, Issues: 20, Pages: 1908-1918; November 10, 2021

→ This publication presents the findings of a Working Group of international experts who evaluated the effectiveness of all currently used cervical screening methods in reducing cancer incidence and mortality. The methods assessed included cytology, liquid-based cytology, HPV testing, visual inspection with acetic acid (VIA) and Romanovski Giemsa staining. In addition, the Working Group reviewed and formulated a consensus statement on the comparative effectiveness of the HPV tests compared to cytology and compared to cotesting.



### 2.2 Learning resources and events

### Learning resources and events outputs

Main ambitions of the MTS 2021-2025:

- Training of the next generation of scientists
- Support of capacity-building in LMICs

#### KPIs:

- IARC Learning portal
- Attendees of courses, and attendees from LMICs
- Collaborations with the WHO Academy (case study)

Source: LCB

Education is an important part of IARC's mission, as described in the Agency's Statutes: "The Agency shall carry out a programme of permanent activities. These activities shall include: [...] the education and training of personnel for cancer research." The ambition of IARC is to contribute to lifelong learning of researchers and health professionals worldwide, to stimulate research in cancer epidemiology, as well as to develop capacities in priority areas of the Agency, such as cancer surveillance, cancer early detection, implementation research, or cancer epidemiology.

### Learning resources: the IARC Learning portal

Launched at the end of 2019, the IARC Learning portal is a key part of the infrastructure that supports the implementation of IARC Learning and Capacity-Building activities planned in the MTS. In 2021–2023, the IARC Learning portal was the backbone, hosting and disseminating to a wide audience an increasing number of

IARC learning and teaching resources.

If one focuses on self-learning, 10 sets of resources were produced during the period 2021–2023. This includes relatively small self-paced modules created based on content from webinars, such as, for example, "COVID-19 and Cancer Screening", and also large learning programmes, consisting of several modules, such as the CanScreen5 or Cancer Prevention Europe programmes. The IARC Learning portal is also the entry point to three free thematic learning platforms:

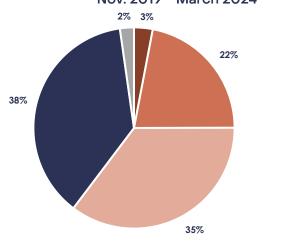
- Cancer Prevention and Early Detection;
- the IARC-ESMO Learning and Capacity-Building Initiative on Cancer Prevention (formerly the World Cancer Report Updates);
- Biobanking.

This platform links to the IARC WebTV, including the IARC Summer School video channel, as well as to educational webpages from other IARC-led projects and initiatives, such as the Global Initiative for Cancer Registry Development (GICR) and the Human Exposome Assessment Platform (HEAP).

The IARC Learning portal attracts an increasing audience. Since November 2019, 5995 people have created an account on the portal to freely access its learning resources. At the beginning of the IARC MTS 2021–2025, the portal was well established and entering a phase of expansion in terms of both resources available and users. In 2021–2023, 4238 new users registered to the IARC Learning portal. Overall, users registered from 172 countries, including 60% LMICs.



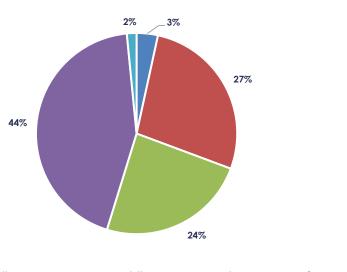
IARC Learning Users Registered by Income Level Category of Country
Nov. 2019 - March 2024



■ Low income ■ Lower middle income ■ Upper middle income ■ High income ■ Information not available

The proportion of IARC Learning users from LMICs increased significantly between 2020 and 2021 before stabilizing for the period 2021–2023. In 2021–2023, new users from LMICs represented 54% of all new users on the platform.

IARC Learning Users Registered by Income Level Category of Country 2021–2023



■ Low income ■ Lower middle income ■ Upper middle income ■ High income ■ Information not available



### Proportion of IARC Learning User Registered from Each World Bank Country Category, per Year

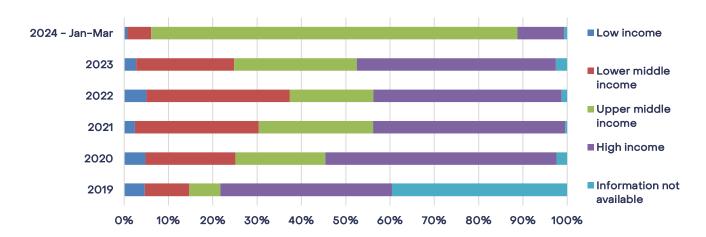


Table 21 highlights the 25 countries with the highest numbers of users registered on the IARC Learning portal. Among these, 17 of the 25 countries (68%) are IARC PS.

Table 21. Top 25 countries by user registration	on the IARC Learning portal
Country <sup>27</sup>	Number of users
Ecuador	1153
India	597
France	254
Spain	241
United States of America	205
Brazil	163
Nigeria	160
United Kingdom	150
Hungary	120
Germany	119
Colombia	108
China	110
Ireland	99
Italy	92
Belgium	87
Mexico	83
Switzerland	81
Canada	64
Netherlands	61
Peru	57
Kenya	55
Sweden	55
Australia	54
Portugal	52
Poland	51

<sup>27</sup> Egypt ranked 29th, with 38 registered users, and Saudi Arabia 55th, with 18 registered users.



### Learning events and participation from LMICs

The LCB Branch, with the support of IARC's scientific Branches, organized 21 courses and webinars in 2021, 26 events in 2022, and 45 in 2023 (Table 22), targeting researchers and health professionals from many countries, in particular LMICs. Most courses were organized online and designed to combine live sessions with facilitated self-learning. They lasted between a few days (Cancer Registration: Principles and Methods) and several months (the IARC Summer School). Part 3.2 on "Capacity-building" provides more information on the IARC Summer Schools. IARC's learning activities are in full evolution with the establishment of the WHO Academy in Lyon, as detailed in the case study below.

	Table 22. Number	of courses and a	ittendees in 201	6-2023 <sup>28</sup>	
Year	No. of courses organized	No. of different countries	No. of courses in LMICs	No. of participants	
2016	36	23	19	1410	
2017	32	16	15	1324	
2018	26	14	11	763	
2019	28	18	15	1083	
2020	16	Onl	868		
2021	21	Onl	1851		
2022	26	Mostly online 1145			
2023	45	Mostly	online	2965	

According to the LCB Branch, the variety of tools and approaches used to organize webinars in 2021, 2022, and 2023 made it difficult to get a clear picture of country participants. However, a representative sample is probably the IARC Summer School public events held in 2023, with 53% of registrations from LMICs (580 of 1102 registered). Apart from webinars, of the 66 courses (face-to-face, online, or blended) organized during the reporting period, 80% mostly targeted LMICs. The remaining courses mostly targeted IARC PS (> 90%). Overall, and based on the data available, it is estimated that close to 70% of IARC course participants came from LMICs during the reporting period.

The development of learning resources and the running of courses rely on multiple partnerships with a whole range of entities: national cancer centres, ministries of health, academic institutions, professional societies, WHO including the WHO Academy, networks, etc.

During the current MTS period, IARC has initiated the development of regional Learning Centres, to consolidate capacity of cancer researchers worldwide. Priority is given to training researchers from LMICs. The objective of the Learning Centres is to jointly organize learning activities, such as the IARC Summer School modules, or learning resources and courses within the framework of existing initiatives. So far, IARC has established two Learning Centres:

- → In China (Beijing) in 2023, with the National Cancer Center of China,
- → In Brazil (São Paulo) in 2024, with the National Cancer Institute of Brazil (INCA).

<sup>28</sup> Source: IARC-LCB, November 2024.



# Collaboration with the WHO Academy

Case study

### **Overview of the collaboration**

The WHO Academy campus is located in Lyon Gerland, close to IARC. It is hosted in a 11 100 m<sup>2</sup> building spread over 8 levels, constructed in 2022 and 2023. Its inauguration is planned in October 2024. The basement is entirely dedicated to simulation areas, where specific temperature and humidity conditions can be reproduced. It will also be used for large-scale simulation exercises for health workers to sharpen their competencies amid realistic scenarios, including mass casualties and disease outbreaks. The ground floor and first floor are dedicated to reception, catering, events, and seminars (agora, auditorium, large work rooms). Floors 2, 3, and 4 are designed to welcome face-toface training, hybrid training, and collaborative work. Floors 5, 6, and 7 accommodate 50 workstations each and will welcome, in autumn 2024, the teams of the WHO Academy and the WHO Lyon Office.

### **Summary**

As stated during the Groundbreaking Ceremony in September 2021, "the mission of the WHO Academy is to provide millions access to the highest quality life-long learning in health", thanks to its campus in Lyon and partners. The WHO Academy is a Department of WHO headquarters with the ambition "to offer multilingual, personalized learning programmes in digital, in-person and blended formats, deploying the latest the-art learning technologies and learning". The WHO Academy is building a single, digital Learning Experience Platform, in order to gather more than 1,400 courses for internal and external learners via 18 different digital learning platforms, currently delivered by WHO across the organization. The Academy aims "to expand access to critical learning to health workers, managers, public health makers and people who provide care in their own homes and communities, as well as to WHO's own workforce throughout the world. Most learners will access the Academy's courses online. The Academy's bespoke platform will be available via desktop and mobile devices, in lowbandwidth settings and with downloadable, offline options. Many courses will use a blended approach, combining in-person and online learning".

WHO has approved an organization chart for the Academy of 75 people. The recruitment of 45 people is planned for 2024, and the remaining 30 in 2025. The WHO Lyon Office, which has been present in Lyon for more than 20 years and helps countries to strengthen their public health systems to better detect, assess, notify, and respond to health emergencies, will join the WHO Academy building with a staff of nearly 30 employees.

As mentioned in the MTS 2021–2025, "the Nouveau Centre's proximity to the future WHO Academy may result in further synergies and opportunities to share resources". Indeed, the cooperation of IARC with the WHO Academy has translated, during the MTS period, into several types of collaborations.

Since 2020, IARC has been involved in the development of the WHO Academy at several levels. As well as contributing to governance and infrastructure aspects, two IARC learning programmes have been developed as part of the development of the first courses of the WHO Academy: the "Comprehensive Learning Programme on Screening, Diagnosis, and Management of Cervical Precancer" and the "Managing Infrastructure for Medical Research Learning Programme".



• In 2022, IARC and the WHO Academy set up a collaboration within the development of the WHO Academy's Learning Experience Platform (LXP). Within the framework of this collaboration, LCB has provided training design expertise to support the development of the LXP, including through advice on key LXP functionalities and testing of demo versions. The WHO Academy team has agreed to create a dedicated Learning Space on the LXP, to which IARC Learning resources/courses will be migrated. IARC will ensure editorial oversight of the IARC Learning space on the LXP and will remain the owner of all IARC-authored courses hosted on its space. Hosting, maintenance, development, and trouble-shooting services will be run by the WHO Academy and will be charged to IARC through a cost-sharing model (50% for IARC and 50% for the WHO Academy). The collaboration was formalized through a memorandum signed in 2023 by both parties.

### **Structure**

#### Links with WHO

The cooperation of IARC with the WHO Academy on the sharing of learning resources, as well as the sharing of local providers represents a new dimension of the collaboration with WHO headquarters, taking place within the Lyon Biodistrict. To date, IARC has given WHO the benefit of its experience on the site, by sharing specifications, regulatory constraints, and service providers. The IARC Learning courses hosted on the WHO Academy platform keep their IARC branding.

#### Governance framework

The IARC Branch in charge of the coordination of this collaboration with WHO Academy is Learning and Capacity-Building (LCB). According to the memorandum of collaboration between IARC and the WHO Academy, meetings with both parties are organized twice a year, to review project activities and agree on next steps.

#### Resources

The team in LCB in charge of the collaboration with the WHO Academy currently consists of 1 employee on RB (P staff, Branch Head) and 1 consultant on EB.

Anticipating the natural obsolescence of the IARC Learning infrastructure and in view of IARC's limited resources, LCB set up the collaboration with the WHO Academy for the development of the WHO Academy Learning Experience System (LXP), allowing the migration of the IARC Learning portal to the LXP. The annual fee IARC will pay the WHO Academy for this hosting and maintenance is evaluated as €5000−10 000, thanks to a pooling effect.

### **Interface with other Pillars and Branches**

The collaborations of IARC with the WHO Academy involves several Branches of the Agency:

Pillar 1	Pillar 2	Pillar 3	Pillar 4		
	Programme on Managing	on Screening, Diagnosis, and	LCB: Coordination of the cooperation with the WHO Academy and interface with the LXP infrastructure		



### **Key Performance Indicators (KPIs)**

The KPIs on the collaboration with the WHO Academy are mainly those dealing with learning courses and events:

	Number of courses and attendees in 2021–2023 <sup>29</sup>									
Year	Year No. of courses No. of different No. of courses No. of organized countries in LMICs participan									
2021	21	On	Online							
2022	24	Mostly	1145							
2023	45	Mostly	2695							

→ In addition to these indicators, it is worth considering the synergies established with the WHO Academy, such as the number of jointly developed courses and the number of shared participants for the learning courses and events.

### **Alignment with IARC MTS 2021-2025**

Collaboration plan with the WHO Academy: According to the IARC MTS 2021-2025, "the WHO Academy seeks to accelerate the development and adoption of evidence-based policy, practice, and research for better health, using the latest technologies in digital and remote learning and capacity-building. As an example of the envisioned cooperation, the Comprehensive Learning Programme on Screening, Diagnosis, and Management of Cervical Precancer, developed by a WHO-wide consortium and led by IARC, will be developed and launched by the WHO Academy during 2021–2022. A partnership with the new WHO Academy in Lyon is expected to result in additional cutting-edge e-learning modules and training events as of 2023".

→ The cooperation and the action plan defined by the LCB with the WHO Academy is perfectly in line with the ambitions of the MTS 2021-2025.

### Integration to the IARC Project Tree

The collaboration with WHO Academy is part of:

- Level 2 Objective of the IARC
   Project Tree "4 Synthesizing and
   mobilizing knowledge and
   strengthening global capacities in
   cancer science", and it
   contributes to the
- Level 3 Objective:
- Objective 4.1: Strengthen global knowledge and global and national capacities in cancer research and science.

### Main challenges and future perspectives

→ The migration of IARC Learning courses/resources and users to the LXP infrastructure is planned in 2024 and it concerns 30–35 courses. The WHO Academy platform is based on open edx, an open-source solution (a GitHub repository with learning resources), requiring some significant development to be fully operational. The WHO Academy team will create a dedicated Learning Space on the LXP, which will be managed by IARC autonomously. IARC will ensure editorial oversight of the IARC Learning space on the LXP and will remain the owner of all IARC-authored courses hosted on its space. IARC will have the flexibility to publish learning



resources under different types of licenses, including Creative Commons licenses, and to autonomously promote IARC learning courses hosted on the LXP. The WHO Academy will ensure the maintenance and further development the LXP infrastructure, including the IARC managed space, and provide trouble-shooting support to IARC in case of problems. In addition to this transfer, in early 2024 IARC replaced its previous video management system, which was obsolete, with associated cybersecurity risks, with the mainstream Vimeo solution.

The main challenge for IARC regarding its collaboration with the WHO Academy is to understand the Academy's model, which is not yet entirely defined. As part of the agreement with the WHO Academy, IARC will have to make sure that the Academy ensures the maintenance and further development of the LXP infrastructure, including the IARC-managed space. IARC will have to invest in linking and integrating its courses with other components of the LXP platforms, to provide relevant synergies with WHO. IARC will also need to work on the evolution of digital learning resources and on the localization of the contents, which includes language translation and adaptation. Some courses that already provide a certification may extend to an accreditation model based on what will be available through the Academy. IARC will have to define with the WHO Academy the evaluation and monitoring system for all the learning courses, which involves traceability for each participant regarding registration,

participation, and evaluation. This is a real challenge knowing that some courses will take place online, on the ground, or with a hybrid format corresponding to blended learning. Although the WHO Academy simulation areas are designed mainly for mass casualties and disease outbreaks, the use by IARC of these areas needs to be explored. Discussions have been initiated in the context of cancer early detection.

#### For more details

- → WHO Academy website
- IARC Learning platform



### 2.3 Training and fellowships

### Training and Fellowships outputs

### Main ambitions of the MTS 2021–2025:

- Training of the next generation of scientists
- Support of capacity-building in LMICs

#### KPIs:

- Number of ECVS overall and from LMICs
- Number and distribution of IARC fellowships overall and from LMICs

Source: LCB

Training is an important part of IARC's activities; beneficiaries of the IARC Research Training and Fellowship programme make up more than one third of the whole personnel of the Agency. Each year, IARC welcomes Early Career and Visiting Scientists (ECVS) who highly contribute to IARC's scientific production, and therefore its impact. Coming to IARC within the framework of the IARC Research Training and Fellowship Programme, these ECVS are trained, moving to the next step of their career while addressing the most urgent research questions relevant to cancer prevention.

The programme is led by the LCB Branch, in close collaboration with all scientific Branches, DAFO, HRO, the Medical Services, the Early Career Scientists Association (ECSA), and the Fellowship Scientific Officer. This programme also involves efficient administrative management to support students and ECVS in their training contracts, visa/residence permit, travel, health insurance, day-to-day liaison, and support.

The main partners of IARC's Research Training and Fellowship programme are national cancer centres, research/academic institutions, mostly in IARC Participating States and LMICs, international entities such as the Union for International Cancer Control (UICC), and a variety of players engaged in cancer prevention research and capacity-building. In 2023, IARC contributed to the creation of a new doctoral school in oncology with Lyon-based partners (Lyon 1 University, INSERM, CLB, and HCL). Based on multidisciplinary skills, the CanBioS doctoral school aims to address the major challenges of cancer research in the fields of diagnostic and therapeutic innovation, understanding the causes and the prevention of cancer. IARC encourages its scientific staff to take the diploma (HDR) for PhD supervision.

#### Number and distribution of ECVS

Table 24 shows the number and the distribution of ECVS during the MTS period. The number of ECVS has increased by 24% between the periods 2014–2021 (pre-COVID-19/COVID-19) and 2022–2024 (post-COVID-19). This can be explained by the success of research Branches in attracting EB funding. There has been a substantial increase in ECVS from LMICs in 2024 (44%), compared with previous years (~25%). Monitoring this figure in the coming years will enable us to see whether this trend is confirmed.

Table 24. Number and distribution of ECVS since 2021 <sup>30</sup>								
Year	Female	Male	Total (March)	From LMICs				
2021	77	36	113	22 (20%)				
2022	98	49	147	35 (24%)				
2023	92	40	132	32 (24%)				
2024	96	52	148	65%				

<sup>30</sup> Source: IARC-LCB, November 2024.



### Number and distribution of IARC fellowships

Table 25 presents the number of IARC postdoctoral fellowships since 2016 (new + second-year renewals). In other words, these figures correspond to postdoctoral scientists funded by centrally managed IARC fellowships. It should be mentioned that since 2019, only candidates from LMICs have been eligible to apply to this IARC programme. After a significant decrease in 2018, the total number of fellowships remains more or less stable (7–9 per year).

	Table 25. Number of IARC Fellowships since 2016 <sup>31</sup>								
Year	Number of IARC Fellowships awarded	Number of Fellows from LMICs							
2016	17 (7 + 10)	10							
2017	14 (7 + 7)	12							
2018	7 (O + 7)	6							
2019	7 (7 + O)	7							
2020	7 (O + 7)	7							
2021	7 (7 + O)	7							
2022	7 (O + 7)	7							
2023	9 (9+0)	9							

## 2.4 Implementation of the MTS and sustainable research

### Implementation of MTS outputs

Main ambitions of the MTS 2021-2025:

- Reduction of ecological footprint
- Digital transformation

#### KPIs:

- Monitoring of carbon footprint
- Compensation programme for international travel

Source: DIR Office, SSR

The MTS 2021–2025 outlines several environmental objectives to reduce IARC's ecological footprint and the environmental impact of its operations. A major step towards achieving these goals was the move to the new headquarters, a state-of-the-art, eco-friendly facility. This transition is complemented by measures such as flexible teleworking arrangements, reducing air travel for meetings and training events, and an increased reliance on e-learning tools. Additional objectives include transitioning to paperless offices and promoting green information technologies.

In 2022, IARC established a Committee for a Sustainable Research Agency, comprising members from all Pillars, the Director's Office, and the DAF Office. This committee is tasked with advancing the MTS 2021–2025 environmental ambitions and aligning IARC's efforts with

the UN Strategy for Sustainability Management in the United Nations System 2020-2030.

#### Its mission includes:

- Positioning IARC as a global model for sustainable research,
- · Coordinating and integrating sustainability into research and support activities,
- Contributing to achieving net-zero emissions by 2030.

<sup>31</sup> Source: IARC-LCB, November 2024.



In 2022 and 2023, the Committee conducted a comprehensive analysis of UN guidelines such as the Greening the Blue Initiative and the Strategy for Sustainability Management in the UN System 2020–2030. Benchmarks and interviews with other WHO entities (e.g. WHO Regional Office for Europe and UN City Copenhagen) and UN agencies (e.g. World Bank, UNITAID, UNDP) provided insights into best practices.

Using these findings, the Committee formulated an action plan aligned with the three steps of the UN Strategy for Sustainability Management:

- 1. Measure the climate footprint: Implementing tools and surveys to track emissions.
- 2. Reduce emissions: Enforcing policies to minimize environmental impact.
- 3. Offset unavoidable emissions: Exploring compensation measures for remaining emissions.

The 2023 action plan includes education and training initiatives, expert networks, and a carbon impact survey after the move to the new headquarters.

Information Technology Services (ITS) developed a prototype software tool to monitor the carbon footprint of IARC duty trips. Although it is not yet fully operational, this tool represents a step towards comprehensive carbon footprint monitoring, addressing one of the MTS KPIs. However, the tool currently does not cover other emission sources, such as energy usage, building operations, IT infrastructure, and waste management. A fully functional version will be necessary to meet the MTS KPI requirements.

In collaboration with ASO, the Committee developed terms of reference in 2024 for a study on IARC's overall environmental impact. This study aims to gather data for a complete carbon footprint analysis, focusing on Scope 3 emissions (indirect emissions from activities such as business travel and supply chain). Data collection will cover areas including:

- Business travel and commuting,
- Energy and fluid consumption,
- Purchases, IT and office equipment,
- Catering and food services.
- Laboratories and biobank operations,
- Waste management.

IARC's sustainability efforts are a work in progress, with significant advances such as the action plan and monitoring tools in development. However, further steps, including defining a compensation policy for international travel and expanding carbon footprint tracking to all operational dimensions, are essential to achieving the Agency's environmental goals and fulfil its commitment to the UN sustainability agenda (see Main conclusions and recommendations: outputs).



### Main conclusions and recommendations: outputs



### **Publications**

During the current MTS (2021–2025), IARC has published an average of 420 publications annually, of which 80% are peer-reviewed articles. On average, each scientific staff member contributes 6 articles per year, although there are disparities among Branches. The NME Branch alone accounts for one third of IARC's publications, and EPIC-related articles make up 9% of the total scientific output. Co-publications between IARC Branches make up only 7% of the total publications. IARC bibliometric analysis confirms the limitations of the h-index, underscoring the relevance of IARC's decision to sign the Declaration on Research Assessment (DORA).

Moving forward, the Secretariat is encouraged to:

- → Adopt the Relative Citation Ratio (RCR).
- → Develop guidelines for annual reviews (PDMS) that incorporate publication ratios and reflect Branch-level contributions.
- → Encourage inter-Branch collaboration and synergies.

### **Learning events and courses**

IARC's learning events and courses have successfully transitioned to a hybrid model (in-person and online), engaging 1000–2000 participants annually. The Agency is also experimenting with the development of regional Learning Centres in Beijing (China) and São Paulo (Brazil). These initiatives should be aligned with IARC's other hubs, such as GICR and CanScreen5.

→ A major challenge lies in establishing synergies with the WHO Academy, which includes migrating IARC learning resources to the WHO Academy platform. To fully realize this partnership, IARC must address key dimensions such as registration and traceability of participants, accreditation, cybersecurity, the economic model, and visibility of IARC's learning activities.

### **Training and fellowships**

Each year, IARC hosts approximately 130 Early Career and Visiting Scientists (ECVS) in Lyon, with 20–25% coming from LMICs. The Fellowship Programme supports 8–9 postdoctoral fellows annually, allowing scientists from LMICs to spend 1–2 years within IARC scientific Branches, significantly contributing to capacity-building. With additional resources, this programme could expand to support more fellowships.

In 2023, IARC collaborated with local partners in Lyon to establish a new doctoral school in oncology.

→ The key challenge will be ensuring IARC's active participation in this school's development while managing the transition for current doctoral students.



### Implementation and sustainable research

Reducing IARC's ecological footprint is a key objective of the MTS 2021–2025. Over the past 4 years, IARC has established a Committee for a Sustainable Research Agency, which has conducted benchmarks and created an action plan aligned with UN guidelines. Key steps include a pilot tool for monitoring the carbon footprint of trips and defining terms of reference for a comprehensive carbon footprint study.

However, these actions remain unimplemented, and compared with other WHO agencies such as Unitaid or the WHO Regional Office for Europe, IARC is lagging behind in environmental policy implementation.

To achieve tangible progress, IARC's environmental policy requires:

- Greater resources and support from senior management,
- → Transitioning from isolated initiatives to a corporate-level ambition and roadmap for sustainability.

## 3. MTS Outcomes

→ The third category of KPIs for evaluating the MTS 2021–2025 focuses on the outcomes, which are the measurable results achieved through IARC's activities. These outcomes encompass partnerships and international collaborations (3.1), capacity building (3.2), dissemination and visibility (3.3), and Open science (3.4).





### 3.1 Partnerships and international collaborations

### Partnerships and international collaborations outcomes

Main ambitions of the MTS 2021-2025:

- → Establishment of partnerships
- Engagement with UN agencies
- → IARC as the leading global cancer authority

#### KPIs:

- International publications with coauthorship
- → International and national Memoranda of Understanding (MoUs), Memoranda of Agreement (MoAs), Collaborative Research Agreements (CRAs), etc., and international consortia (applications and grants)
- International Research Team coordinated with Japan (case study)

**Source**: Director's Office, SSR (RMO and PLW)

Effective international collaborations are essential to IARC's mission, allowing the Agency to build and strengthen relationships with key stakeholders to enhance its global impact. The KPIs on IARC's collaborations are international related international publications with co-authorship. international agreements (MoUs and MoAs), and international formal contracts collaborations with experts) presented through a comprehensive mapping of IARC international collaborations. Although it is still emerging, the Surveillance (LTS) IARC-Japan Long-Term Research Team also represents an interesting initiative, which should be highlighted as part of the MTS evaluation.

### International publications with co-authorship

Table 26 displays the number and proportion of international collaborations in IARC publications. These figures were produced by analysing the percentage of IARC publications whose co-author affiliations include addresses in more than one country. Of the total of 1365 papers published from January 2021 to April 2024 by IARC, 1320

publications (97%) involved international collaboration, including a co-author affiliation from at least one other country. This percentage is slightly above the figures of the former MTS 2016–2020 (93%).

Table 26. Number and proportion of IARC publications with international collaborations  January 2021 – April 2024 <sup>32</sup>											
2021 2022 2023 April 2024 Total											
Number of publications	426 of 438	423 of 440	372 of 386	99 of 101	1320 of 1365						
% of publications	<b>%</b> of publications 97% 96% 96% 98% 97%										

Table 27 presents the top 50 countries co-publishing with IARC from January 2021 to April 2024. The scientific institutions in the European countries as well as the USA and Australia are the main co-authors for IARC international co-publications. Of the top 25 countries for IARC co-publications, 22 are Participating States; the three exceptions are Greece, Colombia, and South Africa.

<sup>32</sup> Source: IARC-PLW, May 2024



	Table 27. Top	50 countries	s for IARC	co-pu	blications in 2	2021- April 20	24 <sup>33</sup>
Row	Country	Publications	%	Row	Country	Publications	%
1	UK	684	51.82%	26	CZECHIA	59	4.47%
2	USA	637	48.26%	27	SINGAPORE	54	4.09%
3	GERMANY	408	30.91%	28	ISRAEL	52	3.94%
4	ITALY	359	27.20%	29	MEXICO	47	3.56%
5	SPAIN	341	25.83%	30	NEW ZEALAND	44	3.33%
6	SWEDEN	294	22.27%	31	PORTUGAL	43	3.26%
7	NETHERLANDS	293	22.20%	32	RUSSIAN FED.	43	3.26%
8	FRANCE	276	20.91%	33	REP. OF KOREA	41	3.11%
9	NORWAY	248	18.79%	34	POLAND	40	3.03%
10	AUSTRALIA	243	18.41%	35	HUNGARY	38	2.88%
11	CANADA	237	17.96%	36	KENYA	37	2.80%
12	DENMARK	236	17.88%	37	MALAYSIA	37	2.80%
13	CHINA	135	10.23%	38	UGANDA	36	2.73%
14	GREECE	127	9.62%	39	COSTA RICA	33	2.50%
15	SWITZERLAND	117	8.86%	40	ARGENTINA	30	2.27%
16	BELGIUM	105	7.96%	41	NIGERIA	30	2.27%
17	AUSTRIA	95	7.20%	42	ZIMBABWE	29	2.20%
18	BRAZIL	95	7.20%	43	MOROCCO	26	1.97%
19	FINLAND	86	6.52%	44	CÔTE D'IVOIRE	24	1.82%
20	JAPAN	86	6.52%	45	SAUDI ARABIA	24	1.82%
21	COLOMBIA	84	6.36%	46	INDONESIA	23	1.74%
22	INDIA	77	5.83%	47	ROMANIA	23	1.74%
23	ISLAMIC REP. OF IRAN	65	4.92%	48	CHILE	21	1.59%
24	IRELAND	60	4.55%	49	CYPRUS	21	1.59%
25	SOUTH AFRICA	60	4.55%	50	MALAWI	21	1.59%

### IARC collaboration mapping

During the MTS 2021–2025, IARC continued to build a strong collaborative global network with strategic partners. IARC signed 3 Memoranda of Understanding (MoUs) In2021, 6 MoUs in 2022, and 8 MoUs in 2023. The titles and the countries of the MoUs are listed below<sup>34</sup>:

#### MoUs signed in 2021:

- Trinidad and Tobago: Memorandum of Understanding with the Caribbean Public Health Agency (CARPHA).
- UK: Memorandum of Understanding with the Royal College of Pathologists (RCPATH).

<sup>33</sup> Source: ibid.



• USA: Memorandum of Understanding with the Cancer Genomics Consortium (CGC).

#### MoUs signed in 2022:

- China: Memorandum of Understanding with the National Central Cancer Registry (NCCR).
- Czechia: Memorandum of Understanding with Charles University (CharlesU).
- India: Memorandum of Understanding with the Indian Council of Medical Research (ICMR)/National Centre for Disease Informatics and Research (NCDIR).
- Switzerland: Memorandum of Understanding with the Union for International Cancer Control (UICC).
- USA: Memorandum of Understanding with the Association for Molecular Pathology (AMP).
- USA: Memorandum of Understanding with the Pan American Health Organization (PAHO).

### MoUs signed in 2023:

- Belgium: Memorandum of Understanding with the European Society of Pathology (ESP).
- Brazil: Memorandum of Understanding with the National Cancer Institute (INCA).
- China: Memorandum of Understanding with the National Cancer Center (NCC).
- Côte d'Ivoire: Memorandum of Understanding with the Programme National de Lutte Contre le Cancer (PNLCa).
- Japan: Memorandum of Understanding with the National Cancer Center (NCC).
- Kenya: Memorandum of Understanding with the Kenya Medical Research Institute (KEMRI).
- France: Memorandum of Understanding with the European Organization for Nuclear Research (CERN).
- UK: Memorandum of Understanding with the World Cancer Research Fund (WCRF).

In addition to these international agreements, a collaboration mapping was conducted to provide a comprehensive overview of IARC's ecosystem. This mapping offers detailed insights into key stakeholders, the nature of their interactions, and their level of influence within IARC's network.

The full analysis of these international agreements is available in the appendices. Below, we present the key figures and main conclusions from the IARC collaboration mapping for 2021–2024. This analysis encompasses IARC co-publications, Collaborative Research Agreements (CRAs), collaborations with international experts, and projects with external budgets.

- → During the 2021–2024 period, IARC had 38 895 collaboration points across all categories, involving 2263 unique organizations. A substantial portion of these collaborations came from co-publications (28 595 collaborations), which underscores IARC's focus on producing research outputs with a wide range of partners. When only direct collaborations were considered, there were 10 300 collaboration points involving 1405 unique organizations.
- → In terms of geographical range, IARC collaborated with partners from 123 countries in total and 91 for direct collaborations (see map below). IARC's collaboration with LMICs is a significant feature of its partnerships. Across all collaboration types, 24% of collaborations involved LMICs, and 50% of CRAs specifically involved LMIC partners. The higher LMIC involvement in CRAs indicates IARC's strategic focus on engaging with resource-limited settings for structured long-term agreements. Experts involved in the Blue Books, Monographs, and Handbooks mainly represented the public sector (75%), with 28% from LMICs, indicating that although the expert group is predominantly from high-income settings, reflecting the concentration of advanced research in these regions, there is still meaningful inclusion from lower-resource environments.
- → The mapping of collaborations also demonstrates that a significant majority of IARC's collaborations are with entities in PS. In 2021–2024, 84% of the organizations that IARC



collaborated with were based in its PS, even when excluding funding entities and focusing solely on direct research collaborations (83%). In comparison, PS are involved in 71% of supporting collaborations, where IARC is not leading. This indicates that when IARC takes a leading role in research, there is a notable increase in the participation of its PS in these collaborations.

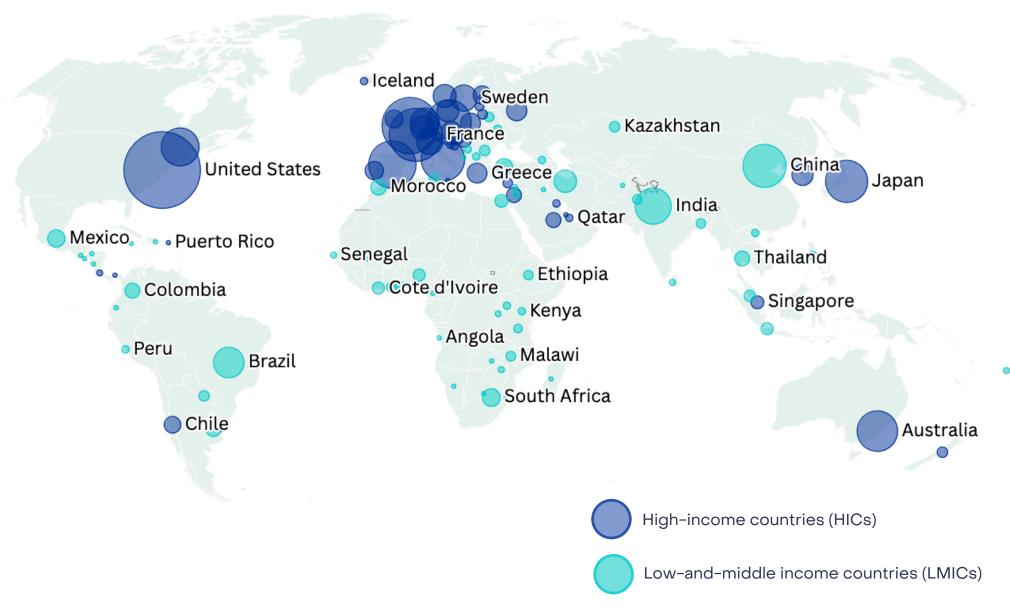
- → Although most of IARC's key collaborators are from PS, some important partnerships exist with institutions in non-Participating States, particularly in LMICs. These collaborations offer strong potential for future new countries to become PS. Mexico and Namibia: These two non-Participating States have established crucial collaborations with IARC, specifically through the National Institute of Public Health of Mexico and the Cancer Association of Namibia. Colombia and Zimbabwe: In Level 4 collaborations, Colombia and Zimbabwe have also emerged as important partners, with institutions such as the University of Antioquia (Colombia) and the University of Zimbabwe and Harare Health and Research Consortium playing vital roles in regional cancer research initiatives. In addition, countries such as South Africa, Argentina, and Greece maintain a significant number of collaborations with IARC.
- → Across all collaboration types, research institutions remain the dominant collaborators, making up 62% of the total organizations. Co-publications involved 71% research institutions. The public sector dominates IARC's collaborations, accounting for 81% of total partnerships. This is even more pronounced in co-publications (85%) and research funders (78%), with 50% of IARC's research funders classified as governmental or intergovernmental organizations. This underscores the strong public sector engagement in IARC's work. Private not-for-profit organizations represent 4% of IARC's total collaborators, with slightly higher engagement (11%) in CRAs. This suggests a specific role for these organizations in formal agreements, but overall they form a smaller portion of IARC's collaborations. Private for-profit entities represent the smallest segment of IARC's collaborators, making up only 2% of total collaborations (with less than 1% in direct collaborations and no funding sourced from this sector). This low representation is expected, given IARC's limited and carefully regulated engagement with the private sector. Hospitals are significant collaborators in co-publications (19%) and CRAs (23%), underlining the clinical impacts of IARC's cancer research. Hospitals are more engaged in expert contributions (33%), showing their importance in advisory roles.



Table 28. Breakdown of IARC collaborations between 2021 and 2024 across different categories of interaction.

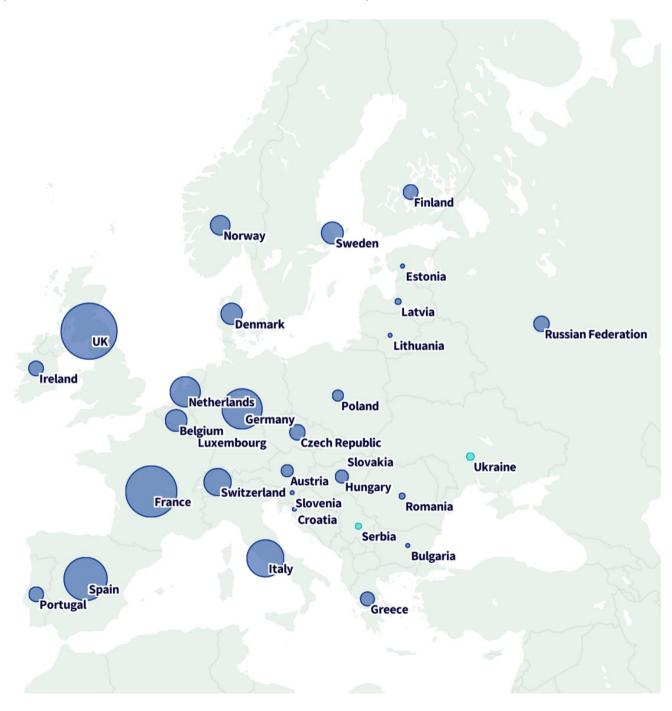
Collaboration type	Total collab.	Unique collab. org.	% Governmental and IGOs	% Not- for-profit	% Private for-profit	% Research org.	% Hospitals	% Public sector	# of countries	% LMICs
Co-publications (all)	28 595	1668	7%	1%	2%	71%	19%	85%	117	26%
Co-publications (IARC leading)	4683	798	9%	2%	0%	68%	21%	86%	78	19%
Expert contributions	2945	517	6%	1%	0%	60%	33%	75%	39	15%
Research funders	2470	360	50%	19%	0%	25%	6%	78%	51	14%
CRAs	199	109	11%	11%	1%	55%	22%	66%	45	50%
Total (all)	38 895	2263	12%	4%	2%	62%	20%	81%	123	24%
Total (direct collaborations)	10 300	1405	18%	6%	1%	54%	21%	80%	91	20%

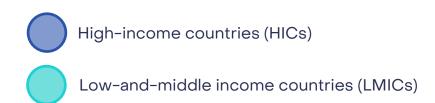






### Map of IARC direct collaborations in 2021-2024 (Europe).







### **Key insights of IARC collaboration mapping**

IARC's collaborations are extensive, spanning a wide range of stakeholders, particularly research institutions and public sector entities. The Agency's efforts are globally distributed, with a strong emphasis on partnerships in LMICs. The mapping of IARC collaborations in 2021–2024 leads to the following conclusions:

- → Global reach and LMICs engagement: IARC's collaboration network spans 123 countries, with strong ties to LMICs. The Agency excels in fostering long-term, sustainable partnerships, particularly through CRAs, which emphasize its commitment to addressing cancer research needs in resource-limited regions.
- → Participating States as core network: IARC's PS form the backbone of its collaborative efforts with public organizations and contribute the largest number of Level 4 and 5 collaborators in its network. Analysis indicates IARC's effectiveness in stimulating direct research collaborations with these countries, surpassing the level of supporting collaborations.
- → Collaborative focus on research institutions: Research institutions are at the heart of IARC's key collaborations, reinforcing its mission to generate and disseminate scientific knowledge on cancer prevention and control. IARC's partnerships with leading actors in the cancer research ecosystem reflect high standards of research excellence.
- → Strong public sector engagement: With 81% of its collaborators being publicly funded entities, IARC's network is closely aligned with national health bodies and academic institutions, ensuring strong support from the public sector for its initiatives.
- → Leadership in international collaboration: Despite its smaller size compared with institutions such as Harvard and MD Anderson, IARC excels in collaboration diversity and breadth, leading the way in multi-institutional partnerships. It has the highest numbers of collaborators per paper and unique organizations per paper.

### Benchmarking the impact of IARC's collaborations

To evaluate IARC's capacity to lead global cancer research collaboration, we conducted a benchmarking analysis comparing IARC's performance with major institutions known for producing high volumes of cancer research. We began by selecting a sample of 12 institutions from the top 50 global producers of cancer research publications (identified in the previous section), ensuring a balanced representation across different regions. The selected institutions were:

- Harvard Medical School (USA)
- UT MD Anderson Cancer Center (USA)
- University of Toronto (Canada)
- Institut National de la Santé et de la Recherche Médicale (INSERM) (France)
- German Cancer Research Center (DKFZ) (Germany)
- Chinese Academy of Medical Sciences/Peking Union Medical College (China)
- Fudan University (China)
- Imperial College London (UK)
- Karolinska Institutet (Sweden)
- Fondazione IRCCS Istituto Nazionale dei Tumori (Italy)
- Erasmus MC (Netherlands)
- University of Sydney (Australia)



For this benchmarking, we focused exclusively on research collaborations reflected in coauthored publications and excluded collaborations related to funding or expert participation. This approach ensures consistency, because we lack comparable data on funding and expert collaborations for the other institutions in the analysis. This analysis focuses exclusively on **direct collaborations** (Levels 2–5) to evaluate IARC's role in driving impactful global partnerships.

#### Analysis:

The results are displayed in Table 29 below:

- → This benchmarking analysis shows that despite its smaller size and expected smaller publication output compared with major institutions such as Harvard, MD Anderson, and Fudan University, IARC outperforms many of these organizations in terms of global collaboration and its ability to connect with diverse research institutions across the world.
- → IARC shows a strong collaboration effort with 4683 collaborations, which is significant given its size. Institutions such as Harvard and MD Anderson have significantly higher paper outputs, making their collaboration-to-paper ratio lower. When collaborations are compared relative to size, IARC's collaboration network is far more extensive than expected, indicating that IARC is leveraging its partnerships effectively to punch above its weight in terms of research collaborations.
- → IARC leads the benchmark in terms of collaborators per paper, with 15 collaborators per paper, the highest among all institutions. In comparison, larger institutions such as MD Anderson (3.8), Harvard (8.2), and Fudan University (1.3) have far fewer collaborators per paper. DKFZ (11.4) and INSERM (14.8) come closest to IARC but still fall short.
- → IARC works with 828 unique organizations, which is highly competitive even when compared with institutions with much larger outputs, such as Harvard (1246) and MD Anderson (1143). This shows that IARC's collaboration network spans across a large number of institutions. Imperial College and DKFZ, with 476 and 660 unique organizations, respectively, are significantly behind IARC in terms of the breadth of collaboration.
- → IARC again leads in terms of unique organizations per paper, with an average of 2.7 unique organizations per paper, far ahead of most other institutions. By comparison, Harvard (0.7), MD Anderson (0.5), and Fudan University (0.2) work with fewer unique partners per paper, indicating that IARC's research outputs are more collaborative and internationally diverse. Imperial College comes close with 2.3 unique organizations per paper. This indicator is particularly telling of IARC's leadership in fostering international collaboration; when we consider all publications involving IARC (including those where it is not the lead), this number drops to 1.4. The fact that IARC doubles its number of unique collaborators when leading a publication underscores its strong role in driving international research partnerships.
- → IARC collaborates with institutions from **78 countries**, the highest figures in the table, surpassing Harvard (71 countries) and the University of Toronto (74 countries). Institutions such as Fudan University (28 countries) and CAMS (28 countries) have a more regional focus, engaging with fewer countries overall.
- → In addition, IARC shows a stronger commitment to LMICs than many other institutions, with 18% of its collaborations involving LMICs, placing it ahead of several other institutions. CAMS and Fudan University show higher percentages, but this is largely due to their regional collaborations within China. When collaborations with China are excluded, IARC's 18% LMIC engagement outperforms their adjusted LMIC rates (CAMS drops to 6%, and Fudan University drops to 3% without China). Karolinska Institutet (17%), Harvard (16%), and MD Anderson (15%) also have strong LMIC engagements, but IARC's focus remains a defining feature of its international collaboration strategy. However, given IARC's mandate as an international agency, the 18% figure may still appear modest, suggesting that there is room for IARC to expand its collaborative efforts with LMICs. This strategy is already being pursued through CRAs, as noted above.



Table 29. Benchmarking IARC among leading cancer research institutions (publications in 2021-2024)35 Unique Unique Total Collaborations % of Collaborations Total Countries collaborating organizations per Institution collaborations publications per publication involved with LMICs organizations publication 309 4683 15 78 18% **IARC** 828 2.7 DKFZ 465 5304 11.4 660 1.4 54 9% Imperial 208 2083 10 476 2.3 8% 49 College **MD** Anderson 2239 3.8 0.5 15% 8461 1143 65 42 4% IRCCS (Milan) 421 3201 7.6 569 1.4 8.2 16% Harvard 1898 15490 1246 0.7 71 379 8% 5607 14.8 533 1.4 47 Inserm 52% (6% without **CAMS** 2275 2065 0.9 471 0.2 28 China) University of 1567 15286 9.8 1202 8.0 74 11% **Toronto** Fudan 41% (3% without 2413 3193 1.3 512 0.2 28 University China) 560 2926 5.2 551 1.0 43 **Erasmus MC** 4% University of 350 7.2 34 8% 2530 448 1.3 Sydney Karolinska 612 2229 3.6 461 8.0 51 17% Institutet

<sup>35</sup> See collaboration mapping in appendices.

### Cooperation with UN agencies

IARC collaborates extensively with the International Atomic Energy Agency (IAEA) and the World Health Organization (WHO) to strengthen global cancer control efforts. This partnership combines IARC's research focus, IAEA's technical expertise in radiation medicine and nuclear technologies, and WHO's broad public health reach. Together, these agencies aim to improve cancer prevention, early detection, and cancer control planning, particularly in LMICs where resources are often limited. One significant outcome of this collaboration is the imPACT (integrated mission of Programme of Action for Cancer Therapy) programme, which is spearheaded by IAEA with contributions from IARC and WHO. imPACT missions assess the needs of Member States in developing cancer control capacities, particularly in cancer registration, detection. and diagnostics. These missions infrastructure. early provide recommendations to support national cancer control efforts and help countries identify gaps in cancer services, laying the foundation for improved prevention and management strategies. IARC's research and data on cancer epidemiology play a crucial role in shaping these assessments and recommendations.

In addition to these collaborations, IARC also interacts with several other international organizations, such as the International Labour Organization (ILO) for worker protection, the United Nations Scientific Committee on the Effects of Atomic Radiation (UNSCEAR) for radiation protection, the UN Environment Programme (UNEP) for environmental protection, and the Food and Agriculture Organization of the UN (FAO) for nutrition.

### Cooperation with UICC

The collaboration between IARC and the Union for International Cancer Control (UICC) is a crucial alliance in the global fight against cancer. Together, these organizations work to advance cancer research, improve prevention efforts, and strengthen cancer control policies around the world. IARC, as the specialized cancer research agency of WHO, and UICC, as a leading global network of cancer organizations, share a mission to reduce the global cancer burden. Their collaboration combines IARC's scientific expertise and UICC's extensive network of cancer organizations, enabling impactful, evidence-based cancer prevention and control strategies. One of the key areas of collaboration between IARC and UICC is the promotion of data-driven cancer control policies. IARC's research and its global cancer databases, such as GLOBOCAN, provide invaluable epidemiological data that help countries understand their unique cancer challenges. UICC leverages this information to advocate for stronger national and international policies on cancer prevention, screening, and early detection. By translating IARC's research findings into actionable policy recommendations, UICC plays a vital role in guiding governments to make informed decisions for effective cancer control. One tangible example of this collaboration is its work on World Cancer Day, which is organized annually by UICC. IARC contributes data and research findings that help shape the messaging and materials used to raise awareness on this global day of advocacy. These evidence-based resources allow World Cancer Day campaigns to highlight key cancer prevention strategies, such as reducing tobacco use and promoting healthy lifestyles, tailored to diverse regions and populations worldwide. This collaborative approach ensures that global cancer awareness efforts are grounded in the latest science.

**Educational initiatives** are another important aspect of the IARC-UICC partnership. Both organizations work together to promote training and capacity-building programmes that equip health-care professionals and policy-makers with the knowledge and skills needed to address cancer effectively. For example, IARC and UICC jointly support workshops, fellowships, and seminars focused on cancer prevention, early diagnosis, and research methodologies, especially in LMICs. These programmes aim to build local expertise and empower communities with the tools they need to combat cancer more effectively.

## Population-Based Long-Term Surveillance (LTS) IARC-Japan Team



#### **Members**

Team leaders: Dr Norie Sawada (Senior Visiting Scientist, NME; Chief, Division of Cohort Research, National Cancer Center Institute for Cancer Control (NCCICC), Tokyo, Japan) and Dr Pietro Ferrari (Branch Head, NME).

Team members: The LTS Team comprises 4 IARC team members (2 scientists from CSU and 2 scientists from NME). The Team also includes scientists from the NCCICC, Tokyo, Japan: Dr Tomohiro Matsuda and Dr Rieko Kanehara. Dr Marc Gunter, former NME Branch Head now at the Imperial College London is part of the Team.

→ Dr Isabelle Soerjomataram (Deputy Branch Head; CSU); Dr Hadrien Charvat (Scientist, CSU); Dr Inge Huybrechts (Scientist, NME); Dr Heinz Freisling (Scientist, NME)

### **Objectives**

This inaugural International Team is jointly coordinated by IARC and the Japan National Cancer Center's Division of International Health Policy Research.



The primary aim of the LTS Team is to establish a long-term follow-up research platform focused on studying lifestyle factors before and after cancer diagnosis. The Team

seeks to identify associations between these factors and cancer prognoses, survival, treatment outcomes, and quality of life (QOL) after diagnosis.

Specific objectives include:

- Gather evidence to support improved prognosis for cancer survivors.
- Identify associations between lifestyle risk factors and cancer diagnosis, prognosis, survival, treatment, and quality of life after diagnosis.
- Develop a research platform for cancer survivors using data from cancer registries.

The activities of the LTS Team primarily depend on two major cohorts managed by the collaborating institutions:

- European Prospective Investigation into Cancer and Nutrition (EPIC) cohort
- Japan Public Health Center-based Prospective Study (JPHC) cohort

### Workplan progress

#### Projects and consortia

Building a platform for cancer survivors from cancer registries:

 Examining the feasibility of creating a platform through negotiations with relevant stakeholders.

- Launching a pilot study focused on registering cancer survivors and collecting Patient-Reported Outcome Measures (PROM).
- Gathering questionnaires on quality of life from cancer survivors.
- Evaluating the association of pre- and post-diagnostic lifestyles:
  - Analysing differences in lifestyle before and after cancer diagnosis using existing cohorts (JPHC and EPIC).

#### Governance

#### Monthly LTS Team meetings:

- Administrative updates
- Team member presentations
- Discussion of grant applications (2023–2024)
- Information sharing

#### **Key partners**

Cooperations across IARC Branches
The LTS Team is led by the IARC NME
Branch in collaboration with the Japan
National Cancer Centre. Currently, the
team collaborates with Pillar 1 (CSU),
but does not include participants from
Pillars 3 and 4. In addition, the team
does not currently have ECVSs, such as
PhD students or postdoctoral
researchers.

Collaboration with external partners
The LTS Team collaborates with several
external partners, including:

- EPIC (European Prospective Investigation into Cancer and Nutrition)
- JPHC (Japan Public Health Centerbased Prospective Study)
- Asia Cohort Consortium
- Pooling Project of Prospective Studies of Diet and Cancer (DCPP)

- o Investigating the impact of lifestyle and dietary changes on the prognosis of colorectal cancer (CRC) survivors within the JPHC and EPIC studies.
- Preparing and submitting a draft focused on the prognosis of lifestyle and dietary changes in colorectal cancer survivors from the JPHC and EPIC studies.
- Including additional analyses for other cancer survivors.

# • Protocol development for long follow-up platform:

- Implementing a follow-up system for cancer survivors in select areas of the JPHC-NEXT study, based on findings from the pilot study in Project 1.
- Discussing challenges and improvements identified during the pilot study.
- o Developing an integrated protocol for the long follow-up platform.

#### Applications and grants

 Previous applications: Applications to the World Cancer Research Fund (WCRF) have been rejected, and applications were submitted to the National

Cancer Institute (NCI) and the National Institutes of Health (NIH).

• Future plans: A new application to WCRF is planned for the 2024-2025 funding cycle.

## **Main innovations**



- Development of a long-term cancer surveillance platform: Focused on monitoring lifestyle factors before and after cancer diagnosis.
- International collaboration: The team leverages partnerships between IARC and the National Cancer Center (NCC) in Japan.

# **Contributions to MTS implementation**

#### Fundamental priorities

The work plan of the LTS Team aligns with two fundamental priorities of the MTS 2021-2025:

- → Data for action: Enhancing the understanding and utilization of data for effective cancer control.
- → Understanding the causes of cancer: Investigating the factors that contribute to cancer incidence and outcomes.

# Main challenges

- **Pilot study support:** The pilot study in Japan requires additional support from IARC, which is currently under discussion with CSU.
- Grant acquisition: The team has not secured any grants in the past two years, despite applications submitted to the World Cancer Research Fund (WCRF) and the National Institutes of Health (NIH). The team is encouraged to reassess and enhance its resource mobilization strategy.

# **Next steps**

According to the LTS Team, the forthcoming steps for the development of the Research Team include:

- → Feasibility assessment: Further evaluating the viability of conducting research on patients with cancer using data from cancer registries as part of the primary objective (Study 1).
- → Enhancing collaborations: Expanding partnerships to explore new projects aimed at identifying novel factors influencing cancer prevention and survival. Key areas of focus include:
  - o The balance of plant versus animal protein consumption.
  - The impact of ultra-processed foods, considering the differences between dietary sources in Japan and other HICs.
  - o Incorporating biomarkers into research, although this aspect falls outside the current Team's scope.

## **RECOMMENDATIONS**



- As a relatively new Team operating from two locations (France and Japan), optimal structure and organization have yet to be established.
- ✓ The team leader and co-leader should consider hosting ECVSs or facilitating exchanges between IARC and NCC Japan. They should also involve scientists from Pillar 3 (implementation research) within the Team.
- ✓ Discussions regarding the feasibility of building a research platform for cancer survivors using registry data should be confirmed with the CSU. The Team is encouraged to define a more focused research topic, such as colorectal cancer, based on data available from the Japanese cohorts.
- ✓ The Team should explore opportunities to build upon the G7 cancer initiative to enhance their projects.

## References

- Web page of the LTS Team
- Web page of EPIC
- Web page of JPHC



# 3.2 Capacity building

#### Capacity building outcomes

Main ambitions of the MTS 2021-2025:

- Support of capacity-building in LMICs
- Training of trainers and cancer leaders

#### KPIs:

- → ECVS outcome surveys
- → IARC Summer School (case study)
- Global Initiative for Cancer Registry Development (case study)

Source: CSU, LCB

Capacity-building in LMICs remains a core mission of IARC, as demonstrated by several key programmes:

- Support to ECVS: Highlighted in the outcome survey, this programme focuses on empowering ECVS in LMICs.
- IARC Summer School: A flagship initiative, providing training and knowledge dissemination (case study).
- Global Initiative for Cancer Registry Development (GICR): Including the GICRNet Training of Trainers, this programme builds expertise in cancer registry development in LMICs (case study).
- BCNet Programme: Supporting the development of biobanking infrastructures in LMICs to enhance research capacity (see Biobank case study).
- **REACCT-CAN Consortium:** IARC collaborates with Addis Ababa University (Ethiopia) through the Research and Excellence in African Capacity to Control and Treat Cancer (REACCT-CAN) consortium, which focuses on building capacity among African cancer scientists.

#### Outcome survey 2024: IARC Research Training and Fellowship Programme

As in previous years, a survey was conducted in February–March 2024 to document the outcomes and identify areas for improvement in the IARC Research Training and Fellowship Programme. The survey targeted 146 doctoral students and postdoctoral scientists (including IARC Postdoctoral Fellows) who participated in the programme between 2019 and early 2024.

More than 55% completed the survey (the response rate varied according to the questions). Overall, 68% spent most of their training period at IARC as postdoctoral scientists (of which 13% were IARC Postdoctoral Fellows selected as part of the regular IARC calls for Postdoctoral Fellowships) and 32% as doctoral students; 41% of the respondents are from LMICs (of which 22% have their current residency in LMICs), and 69% are from IARC Participating States. Overall, 93% are currently employed; 75% are still active in cancer research (65%) or noncommunicable diseases (10%), and 63% work in the public sector. Of the doctoral students, 56% have a postdoctoral contract, 9% have a permanent position, and 35% have other types of contracts. Of the postdoctoral scientists, 40% have secured a permanent position, 12% have a tenure-track position, 19% a postdoctoral contract, and 29% have other types of contracts. Half of the postdoctoral scientists manage their own team and funding; 45% of them have received funding related to their stay at IARC, and 72% continue to collaborate with IARC.

Specific attention was given to former IARC Postdoctoral Fellows, to see what they did immediately after their fellowship:

- → 39% took up a position in a high-income country (HIC) that is not their home country;
- → 22% took up a position in a LMIC;
- → 22% moved to a LMIC without having any position;
- → 11% became an IARC scientist;
- → 6% were without any position for a period of several months up to 1 year.

The IARC Return Grant was set up with the objective of helping IARC Postdoctoral Fellows to establish an independent research programme related to IARC's activities, as well as enabling them to gain independence and additional experience as a researcher. The maximum amount of this grant is €10 000 over a 2-year period. Of those IARC Postdoctoral Fellows who applied for



and obtained an IARC Return Grant (35%), more than 80% considered the award beneficial to both their career and their return institution. The benefit was associated with the expansion of their professional network and future grant or funding applications. Most awardees (67%) did not consider the amount of the Return Grant sufficient, specifically for laboratory experiments or to train several other collaborators properly.

Overall, the total number of publications produced during or related to stays at IARC of former doctoral students and postdoctoral scientists was 477, or an average of 6 publications per person (3 for first-author articles); 54% of respondents had developed transferable skills during their training/learning experience at IARC, which are now applied in their current positions (44% partly transferable and 2% not transferable).

Respondents were asked to rate their satisfaction across seven different criteria, as follows:

- level of stipend received;
- working conditions at IARC;
- offers for development of technical and generic skills (e.g. internal courses, seminars, from supervisor, mentors, job application clinics, courses) at IARC;
- support received for career management at IARC (e.g. from supervisor, mentors, job application clinics, courses);
- level of supervision received from IARC supervisor on research project(s);
- collaboration/communication within project team at IARC; and
- choice of host team or host Branch at IARC.

The overall satisfaction rate (combining the "very satisfied" and "satisfied" responses) was 82%. The criteria for which respondents were the most satisfied were the choice of the host team and the supervision received. The criteria that scored below 80% were the level of stipend received (just below 80%) and the support received for career management at IARC (70%).

From the comments provided, the most often cited aspects that needed attention to improve the programme were the level of stipend (to be adapted to the inflation and reviewed more often), the difference in benefits between IARC training contracts and IARC staff contracts (e.g. health insurance offer, pension), the need to have more options for career support and mentoring, and the importance of the training of supervisors.

Related to supervision, an IARC Good Supervisory Practice Framework was developed and implemented in 2024. This will serve as a point of reference and a guideline. At the individual level, the framework will provide a self-assessment and self-monitoring tool, helping supervisors to identify their own strengths and improvement areas. At the Agency level, the framework provides important input to identify key learning and development needs. In addition, the rules of the IARC Research Training and Fellowship Programme are being reviewed extensively in 2024, including aspects such as the level of stipend and the health insurance options. Of note, the mentoring programme set up in the past years has not so far been much used by the IARC community. Based on the alumni, IARC's impact on their career has been decisive (48%) or helpful (48%); 4% judged IARC's impact on their career to be minimal. The most significant career impacts at IARC were its science, its multidisciplinary and multicultural environment, its people (their collaborators, within and outside of IARC), its opportunities for international collaborations, and IARC being a UN/WHO agency.

→ In conclusion, the results of the outcome survey are consistent with data collected in 2012, 2015, 2017, 2019, and 2021 documenting outcomes of the IARC Research Training and Fellowship Programme as a fantastic opportunity for ECVS to gain complementary skills in preparation for a high-level scientific career, and a springboard to become future leaders of cancer research, contributing to the production of evidence that may lead to the adoption of cancer prevention and control measures.



# IARC Summer School

Case study

#### Summary

The IARC Summer School is an IARC flagship programme, dedicated to fostering the lifelong learning of researchers and health professionals worldwide. Over the past few decades, it has played a crucial role in building capacity in cancer research, particularly in LMICs. The programme prioritizes participants from these regions, offering scholarships to support professionals in advancing their expertise.

# **Overview of the programme**

#### Objectives and target audience

The primary aim of the IARC Summer School is to enhance cancer research, epidemiology, and prevention through improving scientific knowledge and developing research skills among global professionals.

The target audience includes:

- cancer registry staff
- epidemiologists
- statisticians
- medical professionals such as physicians and oncologists
- public health specialists
- postgraduate students in public health

Professionals working in cancer epidemiology, cancer registration, and related activities are the primary focus, particularly those from LMICs.

#### History and evolution of the programme

Launched in 2005 under the leadership of IARC Director Dr Peter Boyle, the Summer School was established with two core objectives: training researchers from developing countries, and providing opportunities for them to engage in international collaborative studies. Initially, the Summer School offered two modules: cancer registration and cancer epidemiology. Over the years, the programme has evolved significantly, reflecting advances in the field of cancer research, the needs of participants, as well as the development of other IARC initiatives, such as the Global Initiative for Cancer Registry Development (GICR).

IARC Summer Schools are now held biennially; the latest sessions occurred in 2021 and 2023. During the COVID-19 pandemic in 2021, the format shifted to fully online to comply with pandemic-related restrictions. In its current format starting in 2023, the programme offers a blend of:

- Self-directed learning via diverse activities, including self-paced educational materials and pre-course assignments, coupled with engaging live online sessions featuring multidisciplinary lectures and practical exercises facilitated by IARC faculty,
- A week at IARC for face-to-face activities.



A pre-requisite e-learning programme was introduced in 2023, hosted on the IARC Learning portal and to be completed before applying to the module "Implementing Cancer Prevention and Early Detection". This innovation was accompanied by the launch of a Public Events Series.

Since its inception, the IARC Summer School has trained more than 940 researchers and health professionals. On average, about 70 participants attend the Summer School, with 36 participants in each module representing diverse disciplines and a wide geographical distribution that reinforces its global impact. For example, in 2023, the 70 participants were from 41 countries, primarily from LMICs.

The programme's consistent evolution is evident in IARC's efforts to develop an Alumni Network aimed at understanding the needs of LMIC researchers and co-designing training materials.

#### Methodology and tools

The Summer School, held biennially, currently consists of two modules:

- Introduction to cancer epidemiology: This module focuses on the practical application of epidemiological principles to cancer control, the search for cancer causes, and the evaluation of control programmes.
- Implementing cancer prevention and early detection: This module covers cancer control strategies, risk factors, prevention approaches, and the principles of screening programmes.

The IARC Summer School offers a hybrid learning experience, combining online and in-person sessions. Each module includes an online component (part 1) and an intense 5-day in-person session at IARC (part 2).

During the online portion, participants engage with recorded lectures, quizzes, and live sessions that promote theoretical learning and interaction. A significant aspect of the programme is the group work activity, which begins during the online phase and continues during the in-person segment, fostering collaboration among participants from different regions and disciplines.

During the in-person sessions, participants engage in practical exercises, group assignments, and on-site visits, which help consolidate the theoretical knowledge gained during the online sessions.

The programme also includes on-demand meetings, where participants can connect with IARC scientists to receive guidance on specific projects and explore potential future collaborations.

In 2023, a Public Events Series was launched, consisting of 12 sessions converted into live events open to external attendees. All 12 live events were recorded and made available on the <u>IARC Learning YouTube channel</u>.

Participants have ongoing access to the training materials after the programme concludes. In addition, most lecture-style sessions are recorded and made available on the <u>IARC Learning portal</u> for a wider audience.



	Date & time (CEST) Check your time zone	Module	Title of public event
Replay	Wednesday 31 May 13:00-14:00	PREV	Social inequalities in cancer: the potential for prevention – Read more
Replay	Friday 2 June 13:00-14:15	PREV	Navigating stakeholder engagement: Why is it important? How to begin? – Read more
Replay	Monday 5 June 13:00-15:10	PREV	The WHO global initiatives on cancer: bringing together stakeholders from around the world – Read more
Replay	Wednesday 7 June 13:00-15:10	PREV	Alcohol and tobacco: the two devils of public health – Read more
Replay	Thursday 8 June 13:00-14:00	EPI	State-of-the-art lecture: Diet and cancer - Read more
Replay	Monday 19 June 13:00-14:00	EPI	State-of-the-art lecture: Social inequalities and cancer – Read more
Replay	Tuesday 20 June 13:00-14:00	EPI	State-of-the-art lecture: Occupational and environmental cancers - Read more
Replay	Wednesday 21 June 13:00-14:00	EPI	State-of-the-art lecture: Infections and cancer - Read more
Replay	Thursday 22 June 13:00-14:00	EPI	State-of-the-art lecture: Genetics and cancer - Read more
Replay	Monday 26 June 13:00-14:10	PREV	Cancer screening programmes: implementation and scale-up - Read more
Replay	Tuesday 27 June 13:00-14:30	PREV	Setting priorities in cancer prevention and control - Read more
Replay	Thursday 29 June 13:00-14:00	PREV	What do countries really need to drive policy change in cancer? – Read more

IARC Summer School Public Events 2023 Agenda1.

For the session planned in 2025, the IARC Summer School will give access to 53-57 hours of training (depending on the chosen module) and a certificate of completion for the following components:

- Participation in the online part (2 to 4 weeks): access to self-paced learning resources, quiz, pre-course assignments, initiation of a group work assignment, and attendance of scheduled live sessions with faculty members, facilitators, and other participants.
- Participation in the face-to-face part (5 days): in-person classes, group work preparation, practical activities, site visit for the Prevention module, social activities, etc.



#### **Structure**

#### Governance framework

In 2010, the Education and Training Group (ETR) was created within the Office of the Director to coordinate and promote educational initiatives. This structure was redefined in 2021 as the Learning and Capacity-Building Branch (LCB), aligning with IARC's Knowledge Mobilization focus in the IARC MTS 2021–2025. LCB now oversees all IARC education and training activities, including the Summer School.

The contents, activities, and speakers of the IARC Summer School are defined with two or three IARC scientific coordinators for each module. Those scientific coordinators are also in charge of the selection process of the participants of the IARC Summer School.

#### Resources

In addition to core IARC funding, the IARC Summer School is supported by a variety of funding sources, including contributions from international agencies and regional partners. Over the years, financial support for the Summer School has been provided by various organizations, including the United States National Cancer Institute, the Nordic Cancer Union, and CHG-MERIDIAN.

IARC offers scholarships designed to enable professionals from LMICs and upper-middle-income countries (UMICs) to attend the Summer School. A full scholarship, valued at €3800, covers the registration fee (€1800), travel expenses (€1250), and living expenses (€750).

Scholarships are increasingly supported by external budgetary sources. For example, in 2023, the WHO Regional Office for South-East Asia provided €16 050 to support scholarships for participants from five countries in the WHO South-East Asia Region. This contribution covered up to €3000 per candidate for travel, registration, and living expenses. Selection priorities were given to applicants from public institutions and under-represented areas with limited cancer data.

In partnership with the Union for International Cancer Control (UICC), IARC has also awarded Development Fellowships since 2012, allowing selected Summer School participants to return to IARC for further training and collaboration. These fellowships, supported through short-term development funding, cover costs up to €3000 per awardee. The mechanism has been put on hold since 2023 by UICC for budgetary reasons.

# Global reach and impact

#### Bridging HICs innovation with LMICs access

The IARC Summer School has made a significant global impact by providing training and capacity-building opportunities to cancer researchers and health professionals from across the world.

The selection process prioritizes applicants from LMICs, which is a central focus of the programme. In recent years, IARC has also strategically reoriented its international courses, focusing particularly on East Asia and Latin America to meet regional needs for cancer research and prevention training.

Each year, more than 90% of the students come from LMICs, and many receive financial support to attend. Participants from these low-resource settings receive a scholarship to cover course fees, and based on the availability of funds, may also receive coverage for travel and living expenses (see II. Structure, 2. Resources).



The impact of the IARC Summer School extends beyond the individual participants. Graduates of the programme frequently note that the knowledge gained has not only furthered their own careers but also contributed to improving cancer research and prevention efforts in their home countries.

Based on the latest outcome survey conducted in 2024, among participants of the IARC Summer Schools in 2017, 2019, and 2021, respondents declared that their participation has fostered lasting collaborations, with 68% of participants establishing ongoing partnerships with IARC and 50% building strong collaborative networks among their fellow participants.



**82%** are still active in cancer research



95% applied what they learned



92% have reused material for themselves

33% have used it to train others



68%
developed
collaborations with IARC

77% of these are still active



developed collaborations with other course participants

68% of these are still active

Based on 46% response rate from the 2024 outcome survey sent to participants of the IARC Summer School 2017, 2019, and 2021.

Statistics on the IARC Summer School's long-lasting impact on cancer research ecosystems.<sup>2</sup>

## Interface with other Pillars and Branches

IARC scientists across all Branches actively participate in the IARC Summer School, providing lectures aligned with their areas of expertise. The module focusing on cancer epidemiology is codirected by NME and ENV, and the module dedicated to cancer prevention and early detection is led by EPR.

In addition, the programme includes on-demand meetings, enabling participants to engage directly with IARC scientists for project guidance, targeted advice, and the potential to explore future collaborative opportunities, which is well reflected in the results of the outcome survey described above.

# **Key Performance Indicators (KPIs)**

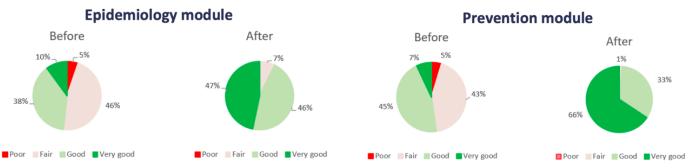
LCB has developed a suite of KPIs, which reflect the IARC Summer School's substantial impact on participant learning and global engagement, and its role in promoting international collaboration and knowledge-sharing in cancer research and prevention:

- Participation and reach:
  - → Number of participants: 70 participants for the 2023 Summer School.
  - → National representation: Participants came from 41 different countries, showcasing the global reach of the Summer School and its diverse audience.
- YouTube and online engagement:
  - → The 2023 Summer School featured 12 live public events, attracting between 260 and 1100 viewers per event. One event had more than 1000 viewers on YouTube.



#### Learning impact:

- → Surveys conducted before and after the course measured the participants' self-perceived confidence in the knowledge and skills covered. The results showed a clear positive impact, with participants reporting substantial improvements in their confidence levels. These gains were further reflected in the written and oral feedback from participants.
- → According to the survey run in 2024, the impact of the IARC Summer School was evaluated as positive, with an overall 97.6% positive impact on career development and a 88.8% positive impact on institutions. Minimal impact was reported by only a few participants (2% for career development and 11% for impact on institution).
- → Participants were asked to rank the impact of the IARC Summer School on their institution, on some key priorities in cancer prevention. Overall, the impact seems consistent across all priorities, with four priorities having received the most positive responses:
  - Use of IARC's publications and findings as evidence for decisions
  - Better understanding and integration of implementation research
  - Better understanding of evolving cancer risk factors
  - Better understanding of the effectiveness of prevention.



Based on 38 responses before and 25 after

Based on 38 responses before and 23 after

Responses from the 2023 IARC Summer School evaluation<sup>3</sup>.

#### Collaboration and networking:

→ 68% of participants reported establishing ongoing collaborations with IARC after the Summer School. In addition, 50% of participants built strong collaborative networks with their fellow attendees (see III. Global reach and impact).

# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

Knowledge mobilization and capacity-building: "IARC is well placed to develop appropriate and tailored capacity-building programmes and to identify the most relevant target audiences for training or mentoring activities."

→ The IARC Summer School plays a pivotal role in knowledge mobilization and capacity-building by offering tailored training programmes designed to equip participants with advanced skills in cancer research (see III. Global reach and impact).



#### Achievements of assigned objectives

Expanding reach and accessibility of the IARC Summer School: "The IARC Summer School in 2023, marking the move of IARC to the Nouveau Centre, will be designed as a blended event. In addition, lecture sessions will be broadcast on the web to allow a maximum number of researchers and health professionals to attend."

→ The 2023 IARC Summer School, held from 15 May to 30 June, adopted a blended learning format that included both in-person and online components. This format accommodated 70 participants from diverse global backgrounds. The Public Events Series attracted external attendees and viewers on YouTube (up to 1100 attendees and viewers for one event)

#### **Integration into the IARC Project Tree**

The IARC Summer School integrates into the IARC Project Tree by contributing to multiple strategic objectives:

- → Level 2 Objective #4: "Mobilizing knowledge for cancer prevention and control."
- → Level 3 objectives: Objective 4.1: "Strengthen global knowledge and global and national capacities in cancer research and science"

# Main challenges and future perspectives

#### Challenges

Resource constraints: One of the primary challenges for the IARC Summer School has been resource allocation. Although the course was held on an annual basis over a decade, the relative decrease in budget for 2016-2017 led to a reduction in some activities. This funding shortfall impacted key training initiatives, necessitating the temporary suspension of critical programmes such as the Summer School or IARC Fellowships, pending the availability of alternative resources or new funding streams. Since then, these activities have been organized on a biennial basis. Such constraints pose a risk to the sustainability of these programmes, which play a vital role in global capacity-building in cancer research.

#### Perspectives

- → IARC Summer School 2025: LCB is currently preparing for the 2025 IARC Summer School, with the application process set to open in November 2024.
- The impact of the IARC Summer School should be leveraged thanks to the setup of IARC Regional Learning Centres. In July-August 2024, the IARC-NCC China Learning Centre implemented the module on Cancer Epidemiology of the Summer School with 36 participants. A new session is planned in 2025. The IARC-Brazil Learning Centre is preparing local sessions of the modules on Cancer Epidemiology in 2025 and on Cancer Prevention in 2026.

#### For more details

→ <u>IARC Summer School</u> website





# **Overview of the programme**

The GICR targets more than 85% of the world's population in Africa, Asia, the Caribbean, Latin America, and the Pacific Islands: more than 7 billion people in more than 160 countries. Six IARC Regional Hubs have been established to work in collaboration to support training, provide consultancies, stimulate research, and foster regional networks. According to the IARC MTS 2021–2025, the GICR will implement six GICR Regional Hubs and associated IARC–GICR Collaborating Centres providing tailored assistance to a set of targeted LMICs, considering needs and national preparedness.

To provide additional support, a network of regional trainers has been formed on five topics: CanReg5, Data quality, Coding and staging, Data analysis, and Childhood cancer. The GICRNet uses a modified

#### **Summary**

The Global Initiative for Cancer Registry Development (GICR) is a partnership programme led by IARC to address disparities in high-quality cancer data across the globe. Launched in 2011, the GICR is based on the commitment of leading cancer organizations to strengthen the quality, availability and use of population-based cancer registry (PBCR) data in LMICs so that they can better inform national cancer control planning. Together with a leading group of partners, IARC supports transitioning countries to build local capacity to collect, synthesize and disseminate findings of cancer data, so that targeted actions can be taken to tackle the rising cancer burden.

An overall aim of the GICR is to provide decision-makers with the information necessary to act. This involves working directly with national partners to assess local cancer data, develop quality improvement plans, and build linkages with the cancer control community in data required for developing and accessing national plans.

Train the Trainer model, in which a group of regional experts are trained in teaching methods, course organization, and material development and assist in sharing knowledge through participation as trainers in regional courses and providing technical support. Designated as IARC GICR Regional Trainers, they serve as a resource to further educate registry staff in each Hub region. To complement formal training, the GICR Mentorship and Twinning Programme provides opportunities for knowledge transfer through peer-to-peer exchanges. The goal is to build local capacity by matching individuals from established cancer registries with those from less-developed registries within the same region to work on specific, in-depth areas of need.

One important milestone of this programme was the launch of an e-learning series of 14 modules developed in partnership with Vital Strategies and the African Cancer Registry Network (AFCRN) and supported by Bloomberg Philanthropies. Available in English, French, and Spanish, the free course offers those interested in population-based cancer registries (PBCRs) the possibility to obtain formal recognition as a Global Certified Cancer Registrar. In addition, a series of consultancies to PBCRs and virtual courses were held during the MTS period on cancer registration (such as the collaboration with the Quito Cancer Registry in Ecuador and the Pan American Health Organization, a series of regional workshops with the WHO Regional Office for the Eastern Mediterranean, and in the Lao People's Democratic Republic with the National Cancer Institute of Thailand), on CanReg5 (in collaboration with the National Cancer Institute of Argentina and Colombia). The annual IARC–GICR Summer School with the National Cancer Center of the Republic of Korea was held virtually in 2022 and in person in 2023.

The GICR programme also brings innovation to registry operations. The E-NNOVATE partnership piloted the linkage of electronic medical records to PBCRs via the world's largest health information management system, the District Health Information Software version 2 (DHIS2).



Working closely with the GICR, IARC also serves as the Secretariat for the International Association of Cancer Registries (IACR), the professional body dedicated to fostering the aims of PBCRs worldwide. After online meetings held during the COVID-19 pandemic, an in-person scientific conference was hosted in Granada, Spain, in partnership with the European Network of Cancer Registries (ENCR).

#### **Structure**

#### Governance framework

The GICR programme is based on a multi-partner initiative including WHO, IAEA, UICC, ACS, CDC, IACR, St. Jude Children's Research Hospital, and Vital Strategies. It brings together international and national agencies committed to improving cancer surveillance at the national level. The governance of the programme relies on three levels of collaboration:

- The global level, to produce global goods applying to all countries, such as the GICR learning modules, to communicate on the programme outputs, and to support resource mobilization,
- → The regional level, with the WHO regional offices to coordinate the GICR work plan, as well as the GICR Hubs, and the Centres of Expertise to run the training and the capacity-building,
- → The national level, to provide directed support, implement quality improvement plans, do site visits, and establish collaborative research agreements. Depending on the countries the main interlocutors of IARC at the local level are ministries of health, registries, or cancer hospitals. Although hospital-based cancer registries are useful for providing information at the hospital level, the GICR programme targets population-based cancer registries (PBCRs) due to their role in cancer control.

#### Links with WHO

GICR is a key programme of the collaboration of IARC with WHO headquarters, and it is part of the IARC-WHO Strategic Workplan for 2023–2025. CSU data, and as such support to GICR, are key for the WHO initiatives on cervical cancer, breast cancer, and childhood cancer. The joint ambition is that "IARC's GICR will be adapted by IARC and WHO as GICR+, upon consensus, to optimally support the provision of relevant indicators to inform and evaluate progress in scaling up the three WHO cancer initiatives and more broadly in the support of the implementation of NCCP". More specifically, the GICR+ aims to define and delineate three workstreams directly relevant to the WHO global cancer initiatives:

- Implementation of PBCRs of high-quality and monitoring of WHO cancer initiatives and/or cancer control plans, taking into consideration WHO cancer initiative and GICR Partner Countries as well as the potential to further develop regional Hubs.
- → Building capacity through the training material including, but not limited to, GICRNet and e-learning.
- Exploring and linking, as possible, CanReg5 with DHIS2 and other facility-based data platforms.

IARC also collaborates with the six WHO regional offices, which are part of the GICR advisory committee, in order to cover the WHO African Region, Eastern Mediterranean Region, South-East Asia Region, Region of the Americas, Western Pacific Region, and European Region. To date, the most active cooperations have been with the Regional Office for Europe and the Regional Office for the Eastern Mediterranean.

#### International collaborative network

From June 2020, IARC entered into a bilateral agreement with St. Jude Children's Research Hospital (USA) to target childhood cancer through the ChildGICR project, an extension of the GICR programme to build national childhood cancer surveillance capacity in LMICs via implementation, education, and research. As part of this, networking workshops involving local



stakeholders were held virtually in four target countries: Georgia; Mexico; South Africa; and Viet Nam. In addition, a set of GICRNet regional trainers was assembled on childhood cancer.

Three IARC-GICR Centres of Expertise were officially launched in 2022, in Côte d'Ivoire, Kenya, and South Africa, in collaboration with Vital Strategies, to improve cancer registration in sub-Saharan Africa. Each Centre of Expertise contributes specific activities towards supporting countries in the region. For example, the Kenya Centre of Expertise at the Nairobi Population-Based Cancer Registry has a focus on training in cancer registration.

#### Resources

The GICR programme, including ChildGICR and GICRNet, relies mainly on 3 full-time staff funded on EB and some contributions of RB staff. IARC wishes to use extra RB funding to consolidate this programme. The resources allocated to the GICR allow it to fund the IARC experts, offer regional training courses, conduct site visits, and support data quality improvement in LMICs. To encourage a sustainable model, IARC does not pay for local registry staff of the partner organizations in LMICs.

## **Interface with other Pillars and Branches**

Collaborations of the GICR programme (CSU Branch – Pillar 1) within IARC include:

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU: The GICR is a major source of data for the GLOBOCAN programme, SURVCAN, and Cancer Incidence in Five Continents (CI5)		examining risk factors and estimates of population attributable fractions.  EPR: Collaborations on linkages with the screening programmes, such as CanScreen5 and country support.	LCB: Collaborations on training and capacity building  ESC: Collaborations on the classification of cancers.

# **Key Performance Indicators (KPIs)**

To examine the efficiency and effectiveness within GICR, a Results-Based Management and Accountability Framework has been developed, in accordance with the UN methodological framework. Key components include a performance measurement strategy to track progress through key indicators, measure outcomes, manage finances, learn, and make adjustments to improve results on an ongoing basis.

The KPIs of GICR focus on:

- → Short-term objectives such as initiation of the IARC Hubs and the number of new agreements.
- → Mid-term KPIs including the number of courses, number of people trained, number of trainers, and the number of new high-quality registries established.
- → To support its **long-term vision**, the GICR programme also is finalizing a Monitoring and Evaluation Framework in 2024 to assist registries with identifying key milestones and the steps needed to progress in data quality.



# **Alignment with IARC MTS 2021-2025**

According to the IARC MTS 2021-2025, "the GICR model will be fully implemented, with resource mobilization efforts intensified under a global fund that allows for a continuing expansion of global and regional partners. Support to LMICs will be enhanced by scaling up the GICR Regional Hubs and associated IARC-GICR Collaborating Centres". The ambition of the programme for the current MTS is that "the GICR will have attained a global fund that ensures Regional Hubs are fully operational, and through global partnerships, a network of trainers, and online courses, there are measurable improvements in the coverage, quality, and networking capacity of registries in 30 partner countries". According to the MTS 2021-2025, "support to the WHO Global Initiative for Childhood Cancer, through a bilateral agreement with St. Jude Children's Research Hospital, will focus on: The development of childhood cancer registration in partner countries; An educational programme, including the provision of standard training materials based on the principles of the GICR-Net; Descriptive economics

# Integration to the IARC Project Tree

The GICR programme is part of Level 2 objective of IARC Project Tree #1, "Describing the occurrence of cancer".

# It contributes to the **Level 3** objectives:

- Objective 1.1: Improve and expand reporting of cancer data and statistics to inform global, regional, and national priorities for cancer prevention and cancer control.
- Objective 1.2: Improve coverage, quality, and utility of cancer registration data worldwide, with an emphasis on LMICs

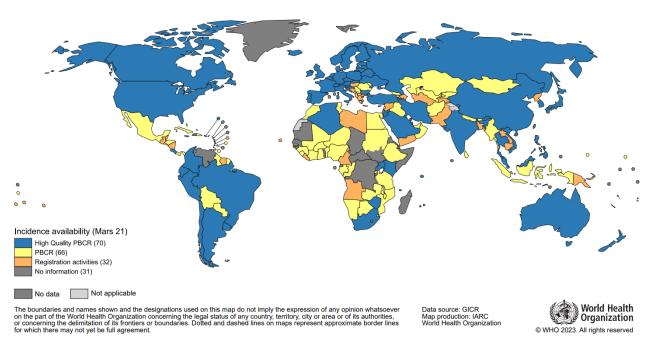
research on (i) the costs of childhood cancer registry implementation, and (ii) an evaluation of familial financial hardship associated with childhood cancer in LMICs".

→ The GIRC, as well as ChildGICR and GICRNet, enable the collection and improvement of cancer data worldwide, with a clear focus on LMICs. This programme is perfectly in line with the objectives of the IARC MTS 2021–2025 and it represents an important contribution to capacity-building in cancer research.

# Main challenges and future perspectives

- According to the GICR, only 1 in 3 countries can report high-quality incidence data (see IARC map below). The ambition of the GICR programme is to help transitioning countries to build their capacity to collect local cancer data, synthesize the data, and disseminate findings, so that targeted actions can be taken to tackle the rising cancer burden. In that context, the IARC action plan consists of the development of six IARC Hubs and Centres of Expertise to support capacity-building and to embed the knowledge within the targeted regions. This approach requires some long-term investments, knowing that approximately one third of the GICR trainers remain active, one third stay passive, and one third leave the GICRNet. Given these figures, the programme would need some additional means to organize some master classes with trainers to maintain the dynamic at the local level and to speed up this process globally.
- GICR represents to some extent the first link of the value chain of cancer research and control. It directly feeds two other major CSU programmes (CI5 and Globocan), as well as research programmes in CSU and other Branches. A next step for the development of GICR will be intensifying the development of global goods tools that provide support across all regions. One such example is from the development of digital tools in the E-NNOVATE project, which seeks to develop a global tool that connects PBCRs to DHIS2, a health information system that is widely used in LMICs. The programme should also take advantage of the new CSU expertise in health economics, in order to identify the costs and resources required for cancer registration in different settings.





Global map on the availability of cancer incidence data in 2021.

 Finally, an important challenge of the GICR programme is related to its recognition. Initiated by IARC, GICR awareness and support from WHO is steadily increasing. IARC would appreciate a reinforced promotion of this programme, including a presentation at the World Health

Assembly. The GICR promotes trust and collaborations as an honest broker to consolidate the quality of cancer data in LMICs and the use of the data for cancer control planning. It relies on a long-term approach to invest in the countries and to build a sustainable model for cancer registries, according to a win-win model.

#### For more details

→ GICR website
→ IACR website



# 3.3 Dissemination and visibility

# Dissemination and visibility outcomes

Main ambitions of the MTS 2021-2025:

- Sharing knowledge and scientific evidence
- Dissemination of information
- Presence in media, on the web and in social media

#### KPIs:

- Printed publications and epublications as public goods
- Organization of scientific conferences and events
- IARC's global reach

Source: PLW and COM

The dissemination of IARC scientific publications can be illustrated by printed publications and e-publications as public goods, and also by access to online tools and databases, such as the Global Cancer Observatory (GCO) platform with GLOBOCAN. In addition, promotion of IARC and increased visibility of the Agency are achieved though media releases and social media presence, as well as conferences and events.

# Printed publications and e-publications as public goods

In 2021–2024, IARC released a series of publications: 9 new publications were released in 2021, followed by 7 in 2022, 10 in 2023, and 12 in 2024. A comprehensive list of these publications, provided as public goods, is presented below.

In 2024, IARC also introduced the GLOBOCAN 2022 estimates, the latest iteration of the Global Cancer Observatory (GCO), an interactive, web-based platform

that offers comprehensive global cancer statistics to support informed decision-making in cancer control and research.

#### Main publications in 2021:

#### WHO Classification of Tumours

- WHO Classification of Soft Tissue and Bone Tumours, 5th edition (PDF and print)
- WHO Classification of Female Genital Tumours, 5th edition (PDF and print)
- WHO Classification of Thoracic Tumours, 5th edition (PDF and print)

#### IARC Monographs

- Volume 126, Opium Consumption (PDF)
- Volume 127, Some Aromatic Amines and Related Compounds (PDF)
- Volume 128, Acrolein, Crotonaldehyde, and Arecoline (PDF)

#### IARC Scientific Publications

Cancer Incidence in Five Continents, Volume XI, IARC Scientific Publication No. 166 (PDF and print)

#### Non-series publications

 Patterns of Care for Women with Breast Cancer in Morocco: An Assessment of Breast Cancer Diagnosis, Management, and Survival in Two Leading Oncology Centres (PDF)

#### **IARC Biennial Reports**

• IARC Biennial Report 2020-2021 (PDF)



#### Main publications in 2022:

#### WHO Classification of Tumours

- WHO Classification of Central Nervous System Tumours, 5th Edition, Volume 6 (PDF and print)
- WHO Classification of Urinary and Male Genital Tumours, 5th Edition, Volume 8 (PDF and print)

#### IARC Monographs

- Volume 129, Gentian Violet, Leucogentian Violet, Malachite Green, Leucomalachite Green, and CI Direct Blue 218 (PDF)
- Volume 130, 1,1,1-Trichloroethane and Four Other Industrial Chemicals (PDF)

#### IARC Handbooks of Cancer Prevention

Volume 18, Cervical Cancer Screening (PDF and print)

#### Non-series publications

• Cervical Cancer Elimination in Africa: Where Are We Now and Where Do We Need to Be? [joint publication with UICC] (PDF)

#### **IARC Biennial Reports**

CIRC Rapport biennial 2020–2021 (PDF)

#### Main publications in 2023:

#### WHO Classification of Tumours

- WHO Classification of Paediatric Tumours, 5th edition (online and print)
- WHO Reporting System for Lung Cytopathology, 1st edition (online and print)
- WHO Reporting System for Pancreaticobiliary Cytopathology, 1st edition (online and print)

#### As beta versions online:

- Head and Neck Tumours, 5th edition
- Endocrine Tumours, 5th edition
- Haematolymphoid Tumours, 5th edition
- Skin Tumours, 5th edition
- Eye and Orbit Tumours, 5th edition
- Genetic Tumour Syndromes, 5th edition

#### IARC Monographs

- Volume 131, Cobalt, Antimony Compounds, and Weapons-grade Tungsten Alloy (PDF)
- Volume 132, Occupational Exposure as a Firefighter (PDF)

#### IARC Handbooks of Cancer Prevention

Volume 19. Oral Cancer Prevention (PDF and print)

#### **IARC Working Group Reports**

 Best Practices in Cervical Screening Programmes: Audit of Cancers, Legal and Ethical Frameworks, Communication, and Workforce Competencies, IARC Working Group Report No. 11 (PDF)



#### Non-series publications

- Mise en œuvre d'un programme pilote de dépistage du cancer du col de l'utérus intégré dans les services courants de soins de santé primaires au Bénin, en Côte d'Ivoire et au Sénégal (PDF)
- Implementation of a Pilot Cervical Cancer Screening Programme Integrated in Routine Primary Health-Care Services in Benin, Côte d'Ivoire, and Senegal: Repot of a Pilot Project (Care4Afrique) in Three African Countries (PDF)

#### Electronic resources

- Atlas de colposcopia principios y práctica, IARC CancerBase No. 13
- Atlas de colposcopie principes et pratique, <u>IARC CancerBase No. 13</u>
- Atlas de l'inspection visuelle à l'acide acétique du col de l'utérus pour dépister, trier et déterminer l'éligibilité des lésions au traitement ablatif, IARC CancerBase No. 16
- Atlas de la inspección visual del cuello uterino con ácido acético para tamizaje, triaje y evaluación para el tratamiento, IARC CancerBase No. 16
- Atlas of Breast Cancer Early Detection, IARC CancerBase No. 17
- <u>Using HPV tests for cervical cancer screening and managing HPV-positive women a practical online guide, IARC CancerBase No. 18</u>
- <u>Tests VPH pour le dépistage du cancer du col de l'utérus et prise en charge des femmes positives au VPH guide pratique, IARC CancerBase No. 18</u>
- <u>Uso de pruebas de VPH para el tamizaje del cáncer cervicouterino y el manejo de mujeres VPH positivas: una guía práctica en línea, IARC CancerBase No. 18</u>
- Cancer Incidence in Five Continents, Volume XII, IARC CancerBase No. 19

#### **IARC Biennial Reports**

• IARC Biennial Report 2022-2023 (PDF)

#### Main publications in 2024:

#### WHO Classification of Tumours

- WHO Classification of Head and Neck Tumours, 5th edition (online and print)
- WHO Classification of Haematolymphoid Tumours, 5th edition (online and print)

#### IARC Monographs

- Volume 133, Anthracene, 2-Bromopropane, Butyl Methacrylate, and Dimethyl Hydrogen Phosphite (PDF)
- Volume 134, Aspartame, Methyleugenol, and Isoeugenol (PDF)

#### IARC Handbooks of Cancer Prevention

Volume 20A, Reduction or Cessation of Alcoholic Beverage Consumption (PDF and print)

#### Non-series publications

 Assessment of Barriers and Interventions to Improve Cancer Screening Programmes in Latin American and Caribbean Countries: Outcomes of the CanScreen5/CELAC Project (PDF)

#### Electronic resources

- <u>Атлас кольпоскопии принципы и практика, IARC CancerBase No.13</u>
- <u>Атлас раннего выявления рака молочной железы, IARC CancerBase No.17</u>



#### IARC Scientific Publications

- Statistical Methods in Cancer Research Volume V: Bias Assessment in Case—Control and Cohort Studies for Hazard Identification, IARC Scientific Publication No. 171 (PDF)
- Cancer Incidence in Five Continents, Volume XII, IARC Scientific Publication No. 169 (PDF)

#### **IARC Technical Publications**

User's Guide to Essential TNM, IARC Technical Publication No. 48 (PDF)

#### **IARC Biennial Reports**

• CIRC Rapport biennial 2022-2023 (PDF)

#### Traffic and downloads on IARC websites

Table 30 provides a summary of the visitors to IARC websites from 2021 to 2024, including the corporate website and sites dedicated to IARC publications, the *Monographs* programme, and the Global Cancer Observatory. The data reveal a significant increase in both the number of visitors and the visits across all these platforms over the evaluation period, reflecting growing global engagement with IARC's resources.

Т	able 30. Visito	ors to IARC websites	since 2021 <sup>3</sup>	36
Year	Total visitors	Average visitors/day	Total visits	Average visits/day
		<u>www.iarc.who.int</u>		
2021	485 201	1329	640 995	1756
2022	616 267	1688	807 489	2212
2023	653 125	1789	931 580	2552
2024 (1 Jan-31 Oct)	563 435	1853 (304 days)	836 503	2751 (304 days)
		IARC Publications		
2021	301 196	825	395 530	1083
2022	298 090	816	387 914	1062
2023	337 952	926	482 642	1322
2024 (1 Jan-31 Oct)	305 855	1006 (304 days)	432 753	1423 (304 days)
		<u>Monographs</u>		
2021	220 557	604	343 012	939
2022	226 442	620	361 191	989
2023	321 541	881	465 138	1274
2024 (1 Jan-31 Oct)	256 764	844 (304 days)	432 435	1422 (304 days)
		bal Cancer Observator		
2021	540 369	1480	934 557	2560
2022	606 256	1660	1 026 551	2812
2023	597 998	1638	1 207 423	3308
2024 (1 Jan-31 Oct)	919 442	3014 (304 days)	1 665 114	5477 (304 days)

Visit/Session: The number of times a visitor has been to the site (number of individual sessions initiated by all visitors). If a user is inactive on the site for 30 minutes or more, any future activity will be attributed to a new session.

<sup>&</sup>lt;sup>36</sup> Visitor/User: A user that visits a given site. The initial session by an individual user during any given date range is considered to be an additional visit and an additional visitor. Any future sessions from the same user during the selected time period are counted as additional visits, but not as additional visitors.



The tables below shows the top 10 most popular downloads from the IARC Publications website, ranked, in 2021–2024. The large majority of these publications are related to the *IARC Monographs* programme, the *IARC Handbooks* programme, the WHO Blue Books programme, and publications on cancer epidemiology and cancer registration.

Item	ре	f downloads r year
	2021	2020
Scientific Publication 163: Molecular Epidemiology: Principles and Practices	94 823	61 348
IARC Handbooks of Cancer Prevention Volume 8: Fruit and Vegetables	70 481	31 073
Cancer Epidemiology: Principles and Methods	57 886	29 862
Monographs Volume 71: Re-evaluation of Some Organic Chemicals, Hydrazine and Hydrogen Peroxide (Part 1, Part 2, Part 3)	48 148	45 060
Monographs Volume 108: Some Drugs and Herbal Products	39 072	21 293
Monographs Volume 82: Some Traditional Herbal Medicines, Some Mycotoxins, Naphthalene and Styrene	37 699	31 038
Technical Publication 45: Colposcopy and Treatment of Cervical Precancer	34 099	43 387
Technical Report 10: Manual for Cancer Registry Personnel	33 315	35 087
Scientific Publication 161: Air Pollution and Cancer	27 513	61 348
Le cancer dans le monde 2003	27 185	50 685

Item		per of ls per year 2021
Scientific Publication 163: Molecular Epidemiology: Principles and Practices	68 692	94 823
Monographs Volume 71: Re-evaluation of Some Organic Chemicals, Hydrazine and Hydrogen Peroxide (Part 1, Part 2, Part 3)	42 209	48 148
Monographs Volume 82: Some Traditional Herbal Medicines, Some Mycotoxins, Naphthalene and Styrene	36 017	37 699
Cancer Epidemiology: Principles and Methods	35 962	57 886
Technical Publication 45: Colposcopy and Treatment of Cervical Precancer	25 144	34 099
IARC Handbooks of Cancer Prevention Volume 8: Fruit and Vegetables	21 252	70 481
Monographs Volume 79: Some Thyrotropic Agents	20 048	22 660
Le cancer dans le monde 2003	18 678	27 185
Cancer Registration: Principles and Methods	17 584	18 664
Technical Report 10: Manual for Cancer Registry Personnel	15 986	33 315



Item		nber of ds per year 2022
Scientific Publication 163: Molecular Epidemiology: Principles and Practices	63 934	68 692
Monographs Volume 71: Re-evaluation of Some Organic Chemicals, Hydrazine and Hydrogen Peroxide (Part 1, Part 2, Part 3)	42 751	42 209
Cancer Epidemiology: Principles and Methods	35 927	35 962
Monographs Volume 82: Some Traditional Herbal Medicines, Some Mycotoxins, Naphthalene and Styrene	34 226	36 017
Monographs Supplement 7: Overall Evaluations of Carcinogenicity: An Updating of <i>IARC Monographs</i> Volumes 1–42	27 004	15 238
Technical Publication 45: Colposcopy and Treatment of Cervical Precancer	25 465	25 144
Monographs Volume 79: Some Thyrotropic Agents	20 178	20 048
Scientific Publication 165: Tumour Site Concordance and Mechanisms of Carcinogenesis	18 571	14 766
Cancer Registration: Principles and Methods	18 032	17 584
Le cancer dans le monde 2003	17 452	18 678

Item		nber of ds per year 2023
Monographs Volume 71: Re-evaluation of Some Organic Chemicals, Hydrazine and Hydrogen Peroxide (Part 1, Part 2, Part 3)	66 678	35 089
Scientific Publication 163: Molecular Epidemiology: Principles and Practices	56 105	53 615
Monographs Supplement 7: Overall Evaluations of Carcinogenicity: An Updating of <i>IARC Monographs</i> Volumes 1–42	43 055	22 159
Monographs Volume 82: Some Traditional Herbal Medicines, Some Mycotoxins, Naphthalene and Styrene	37 748	27 116
Cancer Epidemiology: Principles and Methods	37 503	29 383
Monographs Volume 88: Formaldehyde, 2-Butoxyethanol and 1- <i>tert</i> -Butoxypropan-2-ol	36 319	9036
Technical Publication 45: Colposcopy and Treatment of Cervical Precancer	31 071	20 883
Scientific Publication 165: Tumour Site Concordance and Mechanisms of Carcinogenesis	24 186	15 230
Monographs Volume 53: Occupational Exposures in Insecticide Application, and Some Pesticides	22 324	6595
Monographs Volume 79: Some Thyrotropic Agents	21 792	16 675

#### Amount of sales of IARC publications

The annual revenue of IARC from sales of publications, including though WHO Press, and e-publications is presented in the table below for the 2017–2023 period. During the current MTS, the total revenue from publications was €1 946 778 in 2021, €2 172 647 in 2022, and €2 286 521 in 2023. The sales from the IARC E-Bookshop, which were not really significant during the former MTS, have increased significantly to represent more than two thirds of total revenue in 2023. In accordance with Resolution GC/56/R12, 75% of revenue is returned to the IARC publications programmes.



Year	Revenue from sales of all publications by WHO Press	Revenue from sales of WHO Blue Books in print by WHO Press	Revenue from sales by WHO paid to IARC	Other revenue from publications (IARC E-Bookshop and royalties)
2017	1 756 548	1 752 327 (99.8%)	1 751 567	12 201
2018	1 280 242	1 272 663 (99.4%)	1 279 970	9 601
2019	1 258 412	1 255 618 (99.8%)	1 262 932	48 079
2020	1 706 737	1 701 531 (99.7%)	1 708 370	228 780
2021	1 465 844	1 461 197 (99.7%)	1 465 844	480 934
2022	1 078 102	1 077 242 (99.9%)	1 078 102	1 094 545
2023	709 323	706 452 (99.6%)	709 323	1 577 198

Revenue in euros (€) from sales of IARC publications.37

The WHO Classification of Tumours Online was launched in September 2019, and during the MTS 2021–2025, there was significant growth in the volume of annual subscriptions. In March 2024, the total number of digital subscribers was nearly 19 000. IARC offers to hospital libraries, pathology units, and other institutional subscribers a bulk discount model and a self-service application. The WHO Blue Books series generated 99% to 99.9% of the overall WHO Press publications revenue for IARC in 2021–2023. Sales of subscriptions to WHO Classification of Tumours Online accounted for approximately 25% of the total net annual revenue in 2021, 50% in 2022 and 69% in 2023.

<sup>&</sup>lt;sup>37</sup> Source: <u>IARC Biennial Report on Publication Activities 2022–2023</u>.



# Global Cancer Observatory

Case study

# **Overview of the project**

#### Objectives and target audience

The GCO is hosted, maintained, and developed by IARC as an interactive web-based platform presenting global cancer statistics to inform cancer control based on IARC's cancer research. The platform provides a visualization of cancer indicators that illustrates the changing scale, epidemiological profile, and impact of the disease worldwide. With a focus on data visualization and interactivity, the GCO makes available a broad set relevant indicators developed collaborative programmes, flagship projects, and studies across a set of subsites. A major focus has been continued enhancements to make the GCO more interactive, user-friendly, and informative, harnessing the most recent technologies available.

Among a number of GCO subsites, Cancer Today currently includes the GLOBOCAN estimates of national incidence, mortality, and prevalence in 185 countries for the year 2022. The target audience includes public health professionals, researchers, policy-makers, and stakeholders involved in cancer prevention and control.

#### History and evolution

The GLOBOCAN project has its origins in the early 1980s, when Dr Max Parkin and his predecessor, Dr Calum Muir, both pioneering cancer epidemiologists at IARC, recognized the need and the possibilities for the development of global cancer burden estimates. Beginning with broad estimates of the numbers of new cases for 12 common types of cancer in different areas of the world for the year 1975, the first detailed country-specific estimates of incidence, mortality, and prevalence by sex and age group for 26 types of cancer were made for 2000. The estimates were periodically updated (to the years 2002, 2008, and 2012) using more recent sources of data and increasingly refined methods of estimation. Software tools to visualize and compare patterns of cancer across countries in earlier years were

#### Summary

The Global Cancer Observatory (GCO) platform is an IARC flagship programme, providing up-to-date indicators of the global Coordinated by IARC's Cancer Surveillance Branch (CSU), the GCO is an interactive webbased platform presenting global cancer research. The platform enables the visualization of cancer data through the Agency's support and collaboration with population-based cancer registries (PBCRs). These include global public goods developed jointly with the International Association of Cancer Registries, including the compilation of high-quality PBCR data within each volume of the Cancer Incidence in Five Continents (CI5) series, several related survival benchmarking studies, and, importantly, the Global Initiative for Cancer Registry Development (GICR) programme, which seeks to accelerate the coverage, quality, and use of PBCR data in transitioning countries.

The GLOBOCAN estimates – statistics on made available for 185 countries and 36 cancer types on the GCO. Updated every 2 years, the national estimates ae based on transparent and reproducible modelling techniques that combine local cancer registry data, vital statistics, and cancer survival. The GCO enables users to explore global cancer statistics, visualize trends, and predict the future cancer burden on the various subsites on the platform. Based on the current estimates for 2022, there nearly 20 million new cancer cases and 9.7 million cancer deaths globally; the most common are cancer of the lung, breast, colorectum, prostate, and stomach. Projections suggest that the global cancer burden could reach 35 million new cases by 2050, emphasizing the critical need for the rapid development and implementation of effective cancer prevention strategies.



made available via a CD-ROM initially but were soon replaced with an online platform that allowed users to generate tables, graphs, and projections of cancer burden up to 20 years into the future.

In 2016, IARC launched the GCO, a comprehensive web-based platform designed to act as a one-stop resource for the exploration of global cancer indicators across the cancer continuum. As previously, CI5 submissions (and WHO national mortality statistics) formed the basis of the GLOBOCAN estimates of national incidence, mortality, and prevalence, and these were included in the Cancer Today subsite of the GCO.

The estimates, disseminated on the GCO for 2018 for 185 countries and 36 cancer types, are now revised and updated by CSU every 2 years. The releases of the 2018, 2020, and 2022 estimates were accompanied by open access articles assessing cancer incidence and mortality variations by world region. Other subsites of the GCO have been developed. Cancer Tomorrow provides tools to predict the future cancer incidence and mortality up to 2040, and Cancer Causes provides estimates of population attributable fractions (PAF) for major risk factors. Cancer Survival has been continually updated during the MTS period to incorporate recent site–specific results from numerous papers published as part of the SURVCAN and International Cancer Benchmarking Partnership (ICBP) Comprehensive Approach to International Cancer Survival Benchmarking (SurvMark) projects. Harnessing the technology used to develop NORDCAN 2.0, as supported by the Nordic Cancer Union (NCU) and the Association of Nordic Cancer Registries (ANCR), Cancer Over Time was launched in November 2021 to enable joint analyses of cancer incidence and mortality trends in about 60 countries.

CSU has recently integrated health economics into its descriptive research, focusing on the economic burden of cancer worldwide. Ongoing projects assess the financial impact of implementing cervical cancer elimination and the economic challenges faced by women with cancer, in collaboration with WHO, among other global partners. Relevant indicators will be incorporated on dedicated subsites of the GCO platform.

#### Methodology and tools

GLOBOCAN data are derived from high-quality sources, including population-based cancer registries and national mortality statistics, with estimates made for incidence, mortality, and prevalence. These estimates are produced using a bottom-up, data-driven approach that ensures transparency and reproducibility. GLOBOCAN is updated every 2 years; the most recent estimates were published in 2022, covering 36 cancer types across 185 countries.

Short-term predictions and modelled mortality-to-incidence ratios are used to improve the accuracy of the estimates. In 2018, uncertainty intervals were introduced, ensuring that the quality, coverage, and timeliness of the source data were taken into account in the estimations. The sources and methods used in compiling each iteration of the GLOBOCAN estimates have been documented and are described on the GCO website.

The information available on the GCO platform includes the following statistics:

- Cancer incidence is the number of new cancer cases arising in a specified population over a given period of time (typically 1 year). It can be expressed as an absolute number of cases within the entire population per year or as a rate per 100 000 persons per year. Incidence information is collected routinely by cancer registries.
- Cancer mortality is the number of deaths due to cancer occurring in a specified population over a given period of time (typically 1 year). It can be expressed as an absolute number of deaths within the entire population per year or as a rate per 100 000 persons per year. Mortality data are provided by national statistical offices.
- The prevalence of a given cancer is the number of individuals within a defined population who have been diagnosed with that cancer and who are still alive at a given point in time.



- The population attributable fraction (PAF) of cancer incidence attributable to a given risk factor is the proportion of cancer cases in an entire population that would have been avoided if exposure to that risk factor had not occurred within the population.
- The cancer survival proportion is the probability of survival after a given period of time since the diagnosis of a cancer; 1- and 5-year survival probability are commonly reported.

The main databases available on the GCO web platform are the following:



GCO database at a glance<sup>38</sup>.

<sup>38</sup> https://gco.iarc.fr/en/projects#database



The information provided by GLOBOCAN is illustrated below:



**Number of new cases** 

19 976 499

**Number of deaths** 

9 743 832

Number of prevalent cases (5-year)

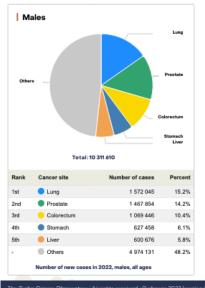
53 504 187

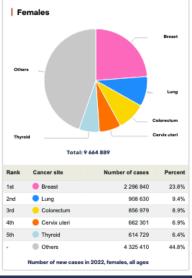
#### Statistics at a glance, 2022

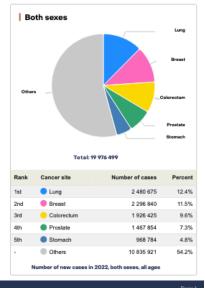
Males	Females	Both sexes
3 972 735 747	3 912 335 034	7 885 070 781
10 311 610	9 664 889	19 976 499
212.6	186.3	196.9
21.8	18.5	20.0
Lung Prostate Colorectum	Breast Lung Colorectum	Lung Breast Colorectum
5 430 284	4 313 548	
3 430 204	4 313 548	9 743 832
109.8	76.9	0.40.002
0 100 201	4010010	91.7
109.8	76.9	91.7 9.6 Lung Colorectum
109.8 11.4 Lung Liver	76.9 8.0 Breast Lung	9 743 832 91.7 9.6 Lung Colorectum Liver
	3 972 735 747  10 311 610 212.6 21.8 Lung Prostate Colorectum	3 972 735 747 3 912 335 034  10 311 610 9 664 889 212.6 186.3 21.8 18.5  Lung Prostate Colorectum Colorectum



#### Top 5 most frequent cancers\*\*







GLOBOCAN statistics at a glance.39



### **Structure**

#### Governance framework

The continued development of the GCO is managed by the CSU Branch, as the entity responsible for the management and execution of the projects on the GCO platform including GLOBOCAN estimations. CSU's work includes data collection, validation, the development of models to estimate core indicators of cancer worldwide, and their dissemination.

#### International collaborative network

#### **Links with WHO**

CSU provides surveillance data and indicators to WHO headquarters in support of the planning and development of national cancer control plans (NCCPs) and in evaluating the success of scaling up the three signature initiatives of WHO focusing on breast, cervical, and childhood cancer (see Global reach and impact).

GLOBOCAN and other related CSU programmes, such as CI5 and GICR, rely heavily on the international support and collaboration of population-based cancer registries. CSU serves as the Secretariat of the International Association of Cancer Registries (IACR), which provides standards and tools to registries worldwide, of which CI5 has been a co-publication since its third volume. GICR is a partnership of many national and international technical and funding bodies. A peer-reviewed publication showcasing the global cancer statistics by world region for the year of estimation is routinely published in collaboration with the American Cancer Society (ACS).

#### Resources

As of February 2024, CSU comprised 33 personnel, including 10 professionals (P), 9 general service (GS) staff, and 14 early-career and visiting scientists (ECVSs).

CSU's core activities, such as maintaining the GLOBOCAN database and publishing the CI5 series of volumes, are funded through IARC's RB. This core funding supports "global goods" crucial for IARC's mission, such as building cancer surveillance capacity in LMICs and disseminating global cancer indicators. However, activities that seek to deliver on GICR's mandate – to build cancer registry capacity, leading to a marked improvement in the availability and use of high-quality surveillance information in LMICs – has largely been made possible through EB funding.

Although CSU continues to apply for competitive grants, direct funding partnerships have proven more successful in recent years and represent the majority of EB funds secured by the Branch.

# **Global reach and impact**

#### Bridging HICs innovation with LMICs access

CSU has consistently produced high-quality research and leadership in global cancer surveillance. The GICR contributes to capacity-building in LMICs. The GICR has developed IARC-GICR Regional Hubs via partnerships such as the African Cancer Registry Network (AFCRN) to develop cancer registration systems in sub-Saharan Africa, improving cancer surveillance across the constituent countries. The AFCRN database provides a solid basis for GLOBOCAN's biennial national estimates in the region.

Recent work in health economics, particularly on the direct and indirect economic benefits of reducing premature cancer mortality worldwide, aligns with WHO's normative guidance and support to WHO regional offices. CSU has also generated key contributions in support of the targets of the WHO Cervical Cancer Elimination Initiative (CCEI), Global Breast Cancer Initiative (GBCI), and Global Initiative for Childhood Cancer, including the provision of technical guidance,



capacity-building, and high-level advocacy in support of the local collection of incidence and survival data by stage at diagnosis within WHO Member States.

#### Impact on public health policies and guidelines

By providing detailed statistics on cancer incidence and mortality, GLOBOCAN serves as a key resource for governments and health organizations. The project enables public health decision—makers to prioritize cancer prevention strategies through a comprehensive understanding of the comparative scale and profile of cancer between and within world regions.

The GLOBOCAN 2022 estimates revealed that nearly 20 million new cancer cases and 9.7 million cancer deaths occurred worldwide. Lung cancer remains the most commonly diagnosed cancer, followed by breast, colorectal, prostate, and stomach cancers. Projections indicate that the global burden of cancer could increase to 35 million new cases by 2050 based on demographic shifts alone. In response, targeted investments in cancer prevention — addressing key risk factors such as smoking, obesity, and infection — could prevent millions of future diagnoses of cancer worldwide.

CSU has conducted numerous studies on the public health impact of cancer and the effectiveness of preventive interventions. For instance, CSU has collaborated with the French National Cancer Institute (INCa) to provide estimates of PAF to guide national cancer prevention strategies.

In collaboration with WHO and the Daffodil Centre, CSU has quantified the global impact of scaling up HPV vaccination, effective cervical cancer screening, and timely curative treatment. The results have informed global strategies to eliminate cervical cancer by estimating when in this century the elimination threshold of fewer than 4 cases per 100 000 women will be reached in 78 LMICs, and the corresponding public health and economic benefits of immediate scaling up of the CCEI.

## **Interface with other Pillars and Branches**

CSU actively engages in cross-agency initiatives and collaborates closely with all other IARC Branches across the three Pillars. These partnerships enable the co-development of new indicators and foster collaboration on research areas of shared interest. The table below highlights some specific collaborations regarding GLOBOCAN.

Pillar 1	Pillar 2	Pillar 3	Pillar 4
	GEM: Collaboration has expanded, particularly through the use of GLOBOCAN data for colorectal cancer studies, a partnership expected to grow as additional datasets are incorporated.	ENV: GLOBOCAN data on attributable fractions are integrated into the World Code Against Cancer Framework.	epidemiological data that informs the epidemiology sections within the WCT volumes, and the classifications are subsequently used by CSU epidemiologists.  CSU collaborates with IHB on cancer incidence data and PAF.



# **Key Performance Indicators (KPIs)**

CSU uses several KPIs to measure GLOBOCAN's success in providing cancer data globally. These KPIs are designed to assess the reach, usage, scientific influence, and policy impact of the data and tools it provides:

- Data quality and coverage: Number of registries, populations and countries included in CI5.
- Scientific impact: The CSU Branch Review in 2022 indicates the figures below regarding citations and publications with statistics coming from the GCO platform.
  - → In 2017–2021, CSU contributed to 292 published papers, which were cited more than 55 000 times. These papers garnered 24 016 citations in 2021 alone, with an average of 190 citations per paper an increase from the previous period (2012–2016), when the average was 38 citations per paper.
  - → GLOBOCAN-related publications were among the most-read and most-cited in top-tier journals. For example, the global cancer burden papers from GLOBOCAN 2018 and 2020 were the two most-read articles in CA: A Cancer Journal for Clinicians (impact factor, 509); the 2020 paper was ranked in the top 0.1% of cited papers in clinical medicine in 2021.
  - → The most-cited articles in the International Journal of Cancer over the past 3 years were CSU-led papers on global cancer burden using GLOBOCAN data. Similarly, a CSU-led paper on the European cancer burden was the most cited in the European Journal of Cancer in the past 3 years.
- Media and public engagement: Media mentions and social media reach.
  - → GLOBOCAN 2018, ICBP SURVMARK-2, and the global impact of alcohol on cancer were featured in more than 900 news outlets worldwide and discussed more than 3,400 tweets and 30 blogs. This broad media coverage reflects GLOBOCAN's role in raising public awareness about global cancer trends and risk factors.
- **User engagement and accessibility**: Website traffic and user interaction with the Global Cancer Observatory (GCO) platform.
  - → Since its launch in September 2018, the GCO has attracted more than 5 million visits, and the number of users has increased steadily over the past 3 years. This highlights the platform's relevance and importance for researchers, health-care professionals, and policy-makers globally.

# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

#### Producing "cancer research that matters":

→ CSU has been instrumental in advancing "cancer research that matters" by providing critical insights into the global cancer burden. CSU's work includes in-depth quantitative assessments of how preventive interventions can avert millions of future cancer diagnoses (see III. Global reach and impact, 2. Impact on public health policies and guidelines).

Becoming an international reference in cancer surveillance by positioning IARC "as a leading authority on global cancer prevention research":

→ CSU's body of work solidifies IARC's position as a leading authority on global cancer surveillance. The transition from purely descriptive research to a broader focus with programmatic and policy implications is aligned with IARC's mission.



Knowledge mobilization and capacity-building: "IARC will ensure that relevant cooperation activities are conducted in a balanced manner across all continents and regions."

→ CSU's international collaborations have been pivotal. Their development of the NORDCAN platform for Nordic cancer statistics and the extensive work on PAF in France (which led to 15 peer-reviewed consensus papers) provided national stakeholders with a robust evidence base for integrating prevention strategies into cancer plans. Moreover. GLOBOCAN's reach now extends to 185 countries, with a strong focus on LMICs (see III. Global reach and impact, 1. Bridging HICs innovation with LMICs access).

#### Achievements of assigned objectives

Dissemination of global cancer statistics: "IARC will disseminate flagship databases and publications such as GLOBOCAN10 and Cancer Incidence in Five Continents (CI5), via the Global Cancer Observatory (GCO) in a timely manner."

- → Disseminating flagship databases and publications, such as GLOBOCAN and the GLOBOCAN 2022 estimates, which were published in February 2022.
- → The GCO platform continues to evolve, incorporating advanced data visualization tools and enhancing usability. In 2021, the launch of Cancer Over Time allowed users to analyze long-term cancer incidence and mortality trends across approximately 60 countries (see I. Overview of the project, 2. History and evolution of the project).

# Integration into the IARC Project Tree

GLOBOCAN integrates into the IARC Project Tree by contributing to multiple strategic objectives, particularly under Level 2 Objective:

→ Level 2 Objective: GLOBOCAN supports Level 2 Objective #1, "Describing the occurrence of cancer," through its comprehensive data collection and analysis on cancer incidence, mortality, and prevalence.

#### Level 3 Objectives:

- Objective 1.1: "Improve and expand reporting of cancer data and statistics to inform global, regional, and national priorities for cancer prevention and cancer control."
- Objective 1.2: "Improve coverage, quality, and utility of cancer registration data worldwide, with an emphasis on low- and middle-income countries (LMICs)."
- → Objective 1.3: "Enhance understanding of global, regional, national, and subnational changes in cancer risk, including in relation to ongoing socioeconomic transitions and social inequalities."
- Objective 1.4: "Enhance understanding of economic consequences of cancer and cancer disparities – descriptive economics."

**Integrating health economics**: IARC will "conduct research on the economics of cancer, including systematic descriptions of the economic burden and generation of evidence to inform national policy-making."

→ CSU has made advances in integrating health economics into its research by developing comprehensive tools and datasets that assess the economic burden of cancer (see I. Overview of the project, 2. History and evolution of the project and VIII. Main challenges and future perspectives). The next step should be to integrate these health economics data as part of the GCO platform.



# Main challenges and future perspectives

#### Challenges

- The data presented in the GCO are considered the best available in each country worldwide. However, IARC is investing in a long-term process to improve the quality of its sources, recognizing the current limitations in the quality and coverage of cancer data, particularly in some LMICs. Therefore, IARC experts work alongside national staff to improve local data quality, registry coverage, and analytical capacity of population-based cancer registries through the GICR.
- One major challenge within CSU is securing sustainable funding for the GICR and descriptive research activities that will continue to improve the quality and coverage of estimates, as well as the range of global indicators included on the GCO platform. IARC's regular budget (RB) funding remains limited, putting pressure on CSU's core activities, including the GICR, which relies heavily on extra-budgetary funding (EB).
- Another significant challenge is navigating increasingly complex data protection standards.
   Such standards demand significant administrative resources, potentially detracting from CSU's primary research goals.
- Strengthening the partnership between IARC and WHO headquarters on cancer statistics, as promoted in the work plan 2023–2025, will help streamline efforts and prevent any risks of duplication, including data and modelling on health economics.

#### Perspectives

- → A key objective of CSU is expanding the GLOBOCAN platform and integrating additional features such as CHILDCAN, which will provide national estimates of childhood cancer incidence. This will be fully integrated into GCO and synced with GLOBOCAN. The GCO will also evolve into a more automated database, allowing registries and institutions to submit anonymized data regularly, enhancing the quality and timeliness of global cancer statistics.
- → The plans to upgrade the GCO platform step by step with some additional indicators regarding surveillance, prevalence by phase of care, Disability-adjusted life years (DALYs), attributable fraction, premature mortality, preventable cancers, treated cancers, and so on.
- → In parallel, the GICR aims to scale up high-quality population-based cancer registries in LMICs. On the global level, the CI5 data across successive volumes will be made available alongside analytical tools for geographical and temporal comparisons, showcased on the reconfigured IACR website.
- → On the health economics front, CSU plans to expand its efforts by appointing a dedicated health economist. By 2030, CSU hopes to integrate findings from its health economics and social inequalities research into GLOBOCAN, creating a tool that will be unique on a global scale. As this work expands, IARC may explore synergies with WHO regional offices, particularly in supporting tools such as those focused on cervical cancer elimination.

#### For more details

- → GCO website
- Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries



## IARC's global reach

Table 31 presents the numbers of press releases and news items produced by IARC since 2021. A slight decrease in the number of news items in 2023 is attributed to parental leave of the staff member responsible, as noted by the COM team. These figures should be considered alongside the findings of the media presence survey, which provides additional context on IARC's visibility and outreach during this period.

Table 31. Number of press releases and news items since 2021 <sup>40</sup>				
Year	Press releases	News items		
2021	14	137		
2022	16	163		
2023	17	126		
2024 (1 Jan-31 Oct)	14 to 31 Oct 2024	123 to 31 Oct 2024		

Table 32 illustrates IARC's presence on the three major social media platforms – X (formerly Twitter), LinkedIn, and YouTube – from 2021 onwards. The data show a consistent improvement in key metrics during the MTS period, particularly in the numbers of followers and subscribers.

A preliminary benchmark suggests that IARC is competitively positioned on social media compared with other key institutions, such as UICC and the WHO Regional Office for Europe. However, some metrics for X (e.g. impressions or likes) are marked as not available (NA), because they require a special subscription for access. This highlights the potential for further data collection enhancements to monitor IARC's social media performance comprehensively.

Table 32. Evolution of the presence of IARC on social media since 2021 <sup>41</sup>					
	Social networks				
	X/Twitter LinkedIn				
Year	Followers	Impressions	Year	Followers	
2021	11 602	NA	2021	11 602	
2022	14 082	930 000	2022	14 082	
2023	~16 300	NA	2023	~16 300	
October 2024	17 281 (on 14 Oct 2024)	NA	October 2024	17 281 (on 14 Oct 2024)	
		YouT	ube		
Year	Subscribers	Views	Year	Subscribers	
2021	1928	104 700	2021	1928	
2022	2957	141 500	2022	2957	
2023	4042	172 664	2023	4042	
October 2024	4787 (on 31 Oct 2024)	111 277 (to 31 Oct 2024)	October 2024	4787 (on 31 Oct 2024)	

<sup>40</sup> Source: IARC-COM, November 2024. 41 Source: IARC-COM, November 2024.



# Organization of scientific conferences and events, and presentations by IARC scientists

Currently, IARC lacks a comprehensive database to systematically track the organization of scientific conferences and events or the oral and poster presentations delivered by its scientists at congresses and invited conferences. Developing such a database would require targeted investments, but the planned introduction of a Customer Relationship Management (CRM) tool, integrated within the forthcoming Enterprise Resource Planning (ERP) system, is expected to enable the efficient collection and management of these data in the future. At present, the primary source of information on IARC's presence at international conferences comes from trip reports submitted by personnel after duty travel. However, this approach provides only a partial picture of IARC's involvement, because an increasing number of scientists now participate via video-conferencing platforms, which are not captured in the current reporting process.

#### IARC's media presence

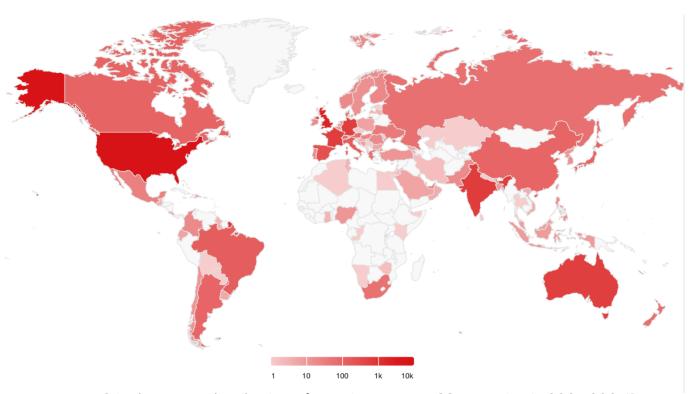
Altmetric data on media citations of IARC's research from 2021 to 2024 provide the following information about IARC's media presence. The detailed version of the analysis is available in the appendices. During this period, 1435 IARC research outputs were referenced across various media channels. In total, IARC was mentioned 65 911 times, with 50 900 mentions on social media platforms (primarily X, accounting for 99%, with other platforms including Facebook, Google+, and Reddit). There were also 14 670 mentions in the press and blogs and 341 mentions in other sources, such as YouTube. Mentions in policy documents were excluded from this analysis, because they are addressed in the next section using a more comprehensive database. Notably, IARC's media presence increased significantly between 2021 and 2024 compared with the previous MTS period (2016-2020). Press mentions were 2.4-fold higher, with an average of 4347 press citations per year and 13 561 social media citations per year, compared with 1781 and 12 197, respectively, in the 2016-2020 period. Table 33 summarizes the media impact of IARC's main programmes, as measured by Altmetric scores in 2021–2024. Publications have been categorized by programme based on keywords in their titles or abstracts. Consequently, some publications that belong to these programmes but do not contain the relevant keywords may be omitted, potentially underestimating the media impact of certain programmes.

Table 33. Media impact of IARC's programmes, according to Altmetric scores in 2021–2024 <sup>42</sup>							
IARC programmes	GLOB OCAN	EP IC	Code Against Cancer	Mutogr aphs	CanScr een5	Mono- graphs	BlueB ooks
IARC papers mentioned in media	9	49	14	1	2	5	13
Total media mentions	5872	16 67	427	32	55	75	199
News mentions	4086	141 3	10	1	5	71	193
Social media mentions	1694	23 3	416	31	50	3	4
Countries reached through social media	50	25	6	0	1	1	0
Countries reached through news	75	65	28	9	9	14	2
Average Altmetric Attention Score	641	50	27	26	21	10	10

<sup>42</sup> Source Altmetric, October 2024



In terms of geographical coverage, IARC's research was cited in 99 countries, including 45 LMICs, in press mentions, as illustrated on the red map below. The Agency has the most media presence in the USA (53% of sources), the UK (14%), India (5%), Germany (4%), and France (4%). The most frequent citations came from MSN in the USA (297 citations), MedicalXpress in the UK (147 citations), The Times of India in India (36 citations), Finanz Nachrichten in Germany (93 citations), and Le Monde in France (95 citations). IARC also appeared in some of the most widely read newspapers in these countries, including one citation in The New York Times<sup>43</sup>, two citations in BILD in Germany<sup>44</sup>, and 47 citations in *The Guardian* in the UK.



1ARC in the press: distribution of mentions across 99 countries in 2021-202445.

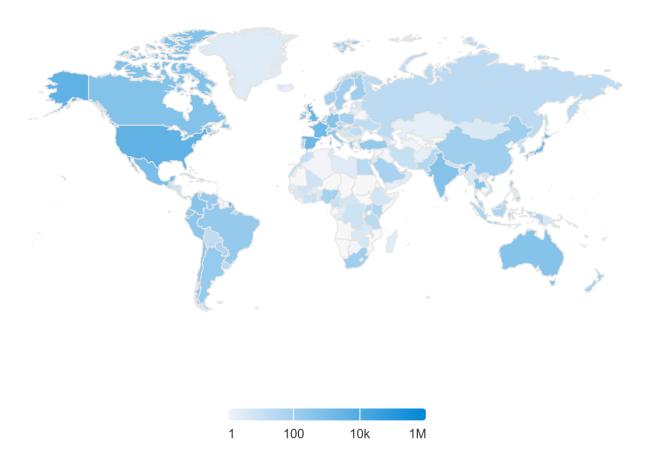
On social media, IARC was mentioned in 183 countries, including 80 LMICs as shown on the blue map below. Social media mentions have an increased activity from users in the USA (11%), UK (7%), Spain (5%), France (4%), and Japan (3%).

45 Source: Altmetric.com

<sup>43</sup> https://www.nytimes.com/2023/07/13/well/aspartame-sweetener-carcinogen.html

<sup>44</sup> https://www.bild.de/leben-wissen/wissenschaft/krebstod-mit-53-starb-der-super-size-me-star-durch-fast-food-6651ab69467fb867762f37f7; https://www.bild.de/ratgeber/2024/ratgeber/unaufhaltsamer-anstieg-bald-doppelt-so-vieleprostatakrebs-faelle-87797010.bild.html





IARC on social media: distribution of mentions across 183 countries in 2021-2024.46

#### IARC's impact in policy documents

To complement the media analysis, an assessment of the impact of IARC's research on policy-making was conducted for the 2021–2024 period. For this analysis, we used the Overton database, a comprehensive platform that tracks the citation of research outputs in policy documents from governments, NGOs, and think tanks worldwide. By capturing how academic research informs public policy, Overton provides a first vision of the real-world impact of scientific findings on decision-making processes. The detailed version of the analysis is available in the appendices.

A total of 1403 publications from IARC were cited in 1915 policy documents. The majority of these documents are standard publications (1541), followed by clinical guidance documents (324), indicating IARC's strong influence on shaping practical health recommendations and public policy.

IARC's influence spans numerous countries, with its research being cited in up to 72 countries by 303 different sources, as illustrated on the map below.





Geographical distribution of sources citing IARC in policy documents in 2021-2024.47

IARC has significantly influenced public health policies. The most impactful policy documents – those that are frequently cited by other policy documents and thus have a greater impact on policy-making – cover key topics such as obesity, tobacco smoking, HIV/AIDS, the COVID-19 pandemic, the human papillomavirus (HPV) vaccine, and screening. However, IARC's influence also extends to less-expected areas such as agriculture, climate change, and poverty.

Most of the research cited in policy documents relates to non-site-specific cancers (61%). However, two specific cancer types stand out in the top 100 IARC articles most cited in policy documents: cervical cancer (22%) and lung cancer (10%). The prominence of cervical cancer is expected, because IARC is a leading agency for the HPV vaccine, which has contributed to efforts towards elimination of HPV-related cancers. However, the notable presence of lung cancer is somewhat surprising, because it is not traditionally one of IARC's top priorities, suggesting that it could potentially become a greater focus. Breast cancer represents only 4% of the research cited in policy documents.

IARC was the lead institution in 48% of the top 100 papers used in policy documents, underscoring its leadership and the recognition of its research excellence by policy-makers. This contrasts with media coverage, which tends to spotlight highly collaborative projects. In addition, it is notable that 75% of the papers used in policy documents were published before 2015 and 30% were published before 2010, emphasizing the long-term impact of research on policy-making.

 $<sup>47 \, \</sup>text{Source: Overton.io; Darker bubbles represent counts} = 1, \, \text{while the larger, lighter bubble represents IGOs.}$ 



# 3.4 Open science

#### **Open science outcomes**

Main ambitions of the MTS 2021–2025:

 Open Access as a cornerstone of Open Science

#### KPIs:

- Open access publications
- Scientific IT Platform (case study)
- Data protection (case study)

Source: SSR, GEM, DAF Office

#### Open science vision

In 2023 the Agency defined, and shared with the Scientific Council, its vision for Open Science, including Open Access Publications, Open Research Data, Opensource software and source code, Open Education, Training, Open Science and Citizen Science, and Biobank open research infrastructure. A document available online presents IARC's vision for Open Science:

"IARC commits itself to the advancement of science and the wide dissemination of knowledge to the benefit of society and cancer prevention, by adopting openness as one of its guiding principles. IARC acknowledges the necessity of balancing the desire for complete openness within scientific research with the need for restrictions where required, due to existing obligations around data protection, security, intellectual

property rights, contractual obligations, legal restrictions and ethical considerations. IARC therefore aims to follow the principle of being "as open as possible, as closed as necessary".

IARC's vision for Open Science is already evident through its Open Access publications and the Scientific IT platform (case study). These initiatives demonstrate a commitment to fostering accessibility and transparency in research while ensuring compliance with data protection standards (case study).

The next step for IARC is to formalize this vision into a comprehensive Open Science Policy, which should include updating the existing <u>Open access Policy</u>.

#### Open Access publications

Open Access (OA) publishing can be defined as the practice of providing online access to scientific information that is free of charge to the user and that is reusable. According to the Agency's Open Access policy, IARC supports and encourages the principles of Open Access: scholarly and scientific literature which is accessible online, free of price and subscription barriers and free of most copyright and licensing barriers. IARC's Open Access Policy went into effect on 1 January 2015, with funding support from the Governing Council Special Fund (GCSF). The IARC policy applies to peer-reviewed journal articles in which the lead or corresponding author is an Agency author or when the Agency takes a lead role in the project.

According to the IARC Biennial Report on Publications 2022–2023, €50 000 per annum has been allocated from the GCSF for article processing charges (APCs) since 2015.

- In 2022, the GCSF supported 28 articles.
- In 2023, it supported 11 articles with the remaining GCSF allocation.

By 2023, Open Access publishing had become fully integrated into operational budget planning, ensuring ongoing support for IARC's commitment to Open Access dissemination.

Table 34 shows the evolution of the number and proportion of IARC's Open Access publications, since 2016. Since the beginning of the current MTS period, IARC has published the majority of its publications in Open Access. This proportion has grown significantly, from 38% in 2016 to 69% in 2024.

<sup>&</sup>lt;sup>48</sup> Definition of Open Access. Berlin Declaration. Max Planck Society. http://oa.mpg.de/lang/en-uk/mpgopen-access-policy/. Accessed 30 May 2012.



Table 34. Number and proportion of Open Access publications since 201649

Year	Number and % of Open Access publications	Number and % of non-Open Access publications	Total number of publications
2016	135 (38%)	223 (62%)	358
2017	151 (42%)	209 (58%)	360
2018	139 (40%)	212 (60%)	351
2019	174 (44%)	217 (56%)	391
2020	225 (49%)	232 (51%)	457
2021	256 (58%)	182 (42%)	438
2022	254 (58%)	186 (42%)	440
2023	264 (67%)	127 (33%)	391
to Oct 2024	184 (69%)	84 (31%)	268

Despite the significant progress in advancing Open Access (OA) publishing, IARC is not yet a member of <u>cOAlition S</u>, unlike WHO or other major scientific organizations. This international consortium promoting Open Science states that "with effect from 2021, all scholarly publications on the results from research funded by public or private grants provided by national, regional, and international research councils and funding bodies must be published in Open Access Journals, on Open Access Platforms, or made immediately available through Open Access Repositories without embargo".

<sup>49</sup> Source: PLW and DIR Office, November 2024.



# Scientific IT platform Case study

# Overview of the platform

#### Objectives and target audience

The IARC Scientific IT (SIT) platform provides access to cost-effective shared centralized computing resources for scientific data storage and analysis, based on modern tools and best practices to facilitate collaborative work.

The objectives of this infrastructure, established at the beginning of the current MTS in 2021, is to offer shared centralized IT resources, in order to contribute to:

- → Collaboration: projects folders can be shared with multiple users,
- → Remote work: using a web browser,
- → Performance: access to powerful machines,
- → Cost-effective: avoids buying powerful personal computers,
- → Security: data are stored in a secured environment and do not need to leave IARC premises,
- → Compliance: required by data owners to store sensitive/personal data.

Initiated by IARC bioinformaticians and computational biologists with the support of ITS/SSR, the SIT platform is a shared facility for all IARC personnel (PhD students, postdoctoral scientists, research assistants, and professional staff members) spread across Branches. IARC's scientific partners will also progressively gain access to the SIT platform to facilitate the collaborations on projects.

#### History and evolution

The creation and deployment of the IARC scientific IT platform were launched following a request from the Governing Council Special Fund in February 2020 (SC/56/4), with the ambition "to provide the necessary infrastructure to store all of IARC's Scientific data safely, consistent with current best practices and worldwide data protection standards, consolidating data centrally to allow efficient and easy access, as well as fostering Open Science through data sharing. Applying the lessons learned from the HPC platform, IARC aims to generalize this approach to all of IARC's scientific data, by providing a unified centralized storage system, including backup and archive".

The scientific IT platform was presented at an IARC-wide seminar and has been open to all IARC personnel since October 2021, following multiple testing phases. This system has been crucial throughout the pandemic to allow IARC personnel to work remotely.

#### **Summary**

The IARC Scientific IT (SIT) platform was developed with the ambition to provide IARC investigators with a centralized and secure platform to store and analyse scientific data. The platform also aims to facilitate remote access to IARC-held scientific data by external investigators without necessitating transfer of individual-level data.

The SIT platform allows storage of confidential data in a secure fashion that is compliant with worldwide data protection standards. In addition, the SIT platform provides a high-performance computing environment for more computationally demanding analyses in a cost-effective fashion.

The SIT platform also contributes to IARC's move into Open Science, specifically by developing a means to allow access to IARC-held data by third-party investigators remotely in a secure fashion. This objective also addressed demands from various funding agencies that require IARC to share scientific data generated within funded projects to external investigators.



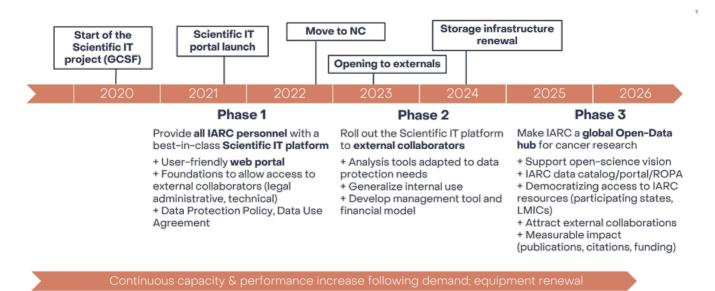
More than 100 projects from all IARC scientific branches were hosted on the platform, before the move to the new headquarters of IARC in Lyon–Gerland in 2022. Detailed documentation was made available to facilitate migration, and various resources including training and interactive and dynamic tutorials were offered to facilitate and optimize the use of the modern computational tools available within the scientific IT platform at IARC. As of January 2023, the SIT platform has evolved into a key infrastructure of the Agency. It offers access to shared centralized IT resources for scientific data storage and analysis, based on modern tools and best practices. It provides a collaborative environment for IARC scientists, allows remote access to high performance computing, is cost effective, and ensures data security and compliance with best practices in data protection. The next step associated with the development of the platform consists in making it accessible to external collaborators, starting with a pilot phase.

This pilot phase has also led to the development of administrative processes, a template Data Use Agreement and technical documentations, and the evaluation and documentation of the SIT platform's future needs and gaps with the support of consultants from Do IT Now S.A.S. In particular, the need for a back-office management tool to manage contracts, users, licenses etc., and the necessity for a financial model enabling the sustainment of these activities in the long term has been pointed out to allow a smooth roll out of the platform to more external users.

Do IT Now S.A.S. also evaluated the SIT platform structure more globally. The strategy to host data on IARC premises rather than relying on third-party cloud infrastructure has been considered fit for purpose based on the evaluation of the current and future IARC specific usage and needs and has led to specific recommendations for the storage and computing infrastructures. Based on these recommendations, the renewal of the storage system started in 2023 with the evaluation of different architecture, technologies, and systems. This was followed by the publication of a Request for Proposal. The proposal offering the best value for money was selected. The implementation took place during the first semester of 2024 and the renewal of the computing infrastructure is planned for 2025.

As a summary, the 3 main phases of the SIT project are summarized in the planning below. They correspond to:

- Phase 1 the creation of SIT platform for all IARC personnel (2021-2022),
- → Phase 2 the access of the platform to external collaborators, (2023-2024),
- → Phase 3 a global Open-Data hub (2025-2026).



Planning 2020-2026 for the project of the IARC SIT platform. 50

<sup>50</sup> Source: Update on data science activities at IARC, SC/60/6, February 2024



#### Methodology and tools

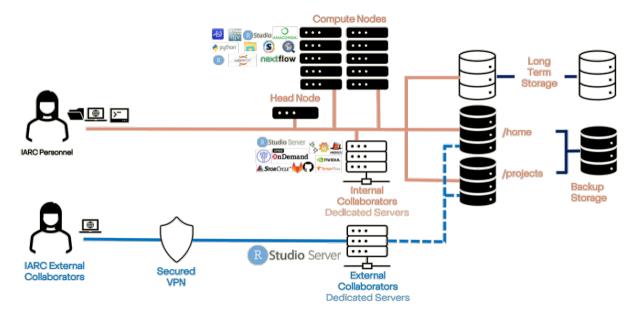
The SIT platform was developed thanks to the competences and involvement of IARC experts in computational biology, bioinformatics, biostatistics, and Information Technology. In an environment with increasing data protection standards, this project was also conducted with support from the Committee for Information Security Oversight (CISO) with IARC Data Protection Officer and designed to provide security and protection of data at every step of its lifecycle.

Through workshops with scientific, IT and the administration, the IARC service provider "Do IT Now" evaluated the SIT platform and documented the SIT User Specification Requirement from both a scientific and an administrative point of view. The final document describes requirements in 6 main areas:

- Data Storage,
- Data Analysis,
- → Back-office Management tool,
- → Financial Model,
- Scientific Data Management tool,
- Security

The SIT platform allows storage of confidential data in a secure fashion that is compliant with worldwide data protection standards. In addition, the SIT platform provides a high-performance computing environment for more computationally demanding analyses in a cost-effective fashion.

The chart below represents the architecture of the SIT platform, according to its main users IARC personnel and external collaborators.



Architecture of the IARC Scientific IT platform.51

<sup>51</sup> Source: Update on data science activities at IARC, SC/60/6, February 2024



#### **Structure**

#### Governance framework

During the MTS 2021-2025, the SIT platform has grown from an IT driven tool to an essential infrastructure requiring collaboration across various services within SSR. Therefore, a reinforced governance system was set up for the SIT platform, in October 2024. The ambition of this new governance is to better face several challenges:

- Evolution into an IARC-wide initiative, benefiting all IARC Pillars,
- Open to external collaborators, especially for major consortia such as EPIC, LC3 and InterLymph,
- Requires collaboration across various administrative and technical teams,
- Requires financial oversight, data protection, cybersecurity, contractual arrangements, procurement, and streamlined collaboration between IARC scientists and external partners.

For this governance, the DAF was formally designated as the governing authority for the SIT platform, with the Data Science Steering Committee (DSSC) serving in an advisory capacity, providing strategic guidance on key decisions. The DAF and the DSSC, represented by its three chairs, work closely together and meet as required to discuss significant matters and ensure informed decision-making.

With more details at operational level, the project of the SIT platform was managed by The Computational Biology, Bioinformatics and Biostatistics (C3B), becoming the Data Science Steering Committee (DSSC) in 2024. The DSSC provides guidance to the SIT team for IT service development and resource planning to support IARC's scientific activities and open-science initiatives.

This committee is composed of three working groups (WG): the bioinformatics WG, the biostatistics WG, and the IT WG. The structure of the committee has been streamlined to increase the interaction between WGs. Responsible officers of the DSSC are Dr Matthieu Foll (GEM) for bioinformatics, Dr Vivian Viallon (NME) for biostatistics, and Mr Nicolas Tardy (ITS-SSR) for scientific IT. Each of them chairs their respective WG and rotates to chair the committee.

#### International collaborative network

The key technical partners for the platform development are: Do It New SAS, Posit for R studio, X9000 for equipment, as well as Dell, NetApp and Storedata for data storage. The scientific software deployment relies mostly on open-source software, notably the NSF-funded "Open OnDemand" portal developed by the Ohio Supercomputer Center (USA).

The three main international collaborative networks using the SIT platform for external access are: EPIC managed by the NME Branch), InterLymph and LC3 managed by the GEM Branch. IARC also collaborates with the Sanger Institute in UK, and the French national high-performance computing infrastructure (GENCI) to have access to additional computing power.

#### Resources

This first phase of the SIT project has been mainly funded by the Governing Council Special Fund in 2020 (€350 000) for storage, computing and software, with additional contributions from scientific Branches and ITS for staff (€215 000).

#### Links with WHO

According to DSSC members, the SIT platform currently does not facilitate specific interactions with WHO headquarters. However, interactions with the WHO Global Initiative on AI for Health are anticipated in the next MTS, as the team is investing in computing infrastructure for AI, including GPU servers.



The main human resources contributing to the SIT platform lie in the ITS team (restructured in 2023–2024), led by the infrastructure manager (P2, Mr Nicolas Tardy), with support from a Linux system analyst (LY5) and an IT system analyst for science (LY5). Dr Matthieu Foll (Scientist, GEM) provides his support on resource planning to support IARC's scientific activities and Open Science initiatives. The Data Protection Officer (DPO), Ms Jolien Jongerius, also provides her support on data protection policies and regulation for the implementation of the SIT platform.

Phase 2 of the SIT project required some additional investments in IT equipment and software, as well as an additional 0.5 FTE IT developer and some services from external providers. During this phase, the renewal of both the SIT and IARC non-scientific (i.e. administrative) storage infrastructures was the opportunity to consolidate IARC storage into a unified system. The main funding sources for the second phase of the project are cost savings from SIT GCSF 2020, unbudgeted assessments from 2023, ITS GCSF 2021 for the unified storage system, and ITS regular budget.

For phase 3 of the project, DAF, BFO, and DSSC members are working on a cost-recovery system, based on discussions with project PIs using the platform internally or interested in deploying such a data hub for their projects with external collaborators. They anticipate an annual budget of €200 000 for the operating costs of the SIT platform. The estimated cost to be back-charged at the IARC level in 2024 is €80 000. In 2025, IARC will also need to invest in renewing its computing capacity. The team is planning to submit a request for this through the Governing Council Special Fund (GCSF).

# **Global reach and impact**

#### Impact on IARC scientific activities

As detailed below in the KPIs, IARC has seen a 22% increase in computing time on the SIT platform high-performance computing cluster in 2 years (4.4 million CPU hours in 2023), a 39% increase in data stored (1218 terabytes), 16% more users, and 74% more projects hosted. Considering these figures and trends, the SIT platform has become an essential scientific infrastructure for IARC.

#### Next steps to support a "Global data hub for cancer research"

The ambition of the Scientific IT platform is to make IARC a global Open-Data hub for cancer research. According to the SIT roadmap, this objective implies to:

- → Support the IARC open-science vision and the contribution of the platform, Define collaborations with key partners such as the WHO Academy,
- → Discuss the potential synergies with Lyon University high-performance computing (HPC) platform in La Doua.
- → Attract additional external collaborations and democratize access to IARC resources (PS, LMICs),
- → Interact with complementary national (e.g. French Health Data Hub) or international data hub (e.g. European Federated Cancer Research data hub; UNCAN.eu).

At an operational level, IARC also needs to:

- → Implement an IARC data catalogue/portal/ROPA in a structured database,
- → Host on the platform IARC's data management plans (DMPs)
- → Prepare the interface between SIT and EPR solutions.
- Anticipate the constraints of health data hosting
- Set up measurable impact indicators (publications, citations, funding.
- → Manage the platform's user community.



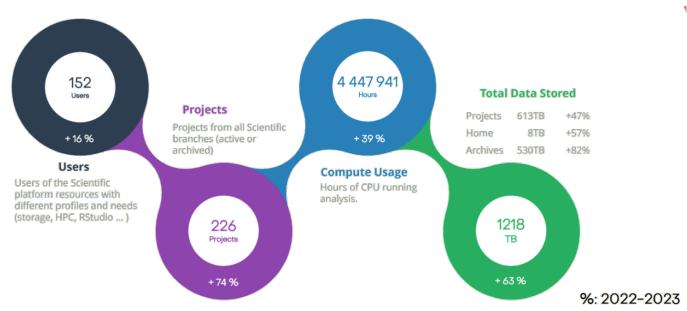
### **Interface with other Pillars and Branches**

The SIT platform is a shared research infrastructure that benefits to all Branches within IARC. At this stage, the main users are within Pillar 2 with the GEM and NME Branches; 90% of IARC scientific projects run their calculations on the SIT platform.

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU: Occasional use of the SIT platform.	GEM: The three main consortia using the platform are InterLymph, LC3, and DISCERN. GEM is one of the main users of calculation and storage (Mutographs project).  NME: The EPIC cohort uses the platform and is one of the main users of calculation and storage (EXPANSE project).	EGM: Use of SIT for calculation.  ENV: The main consortium using the platform is CLIC.  EPR: Use of SIT for calculation.	

# **Key Performance Indicators (KPIs)**

The DSSC has defined a set of indicators related to the implementation of the SIT platform. These KPIs cover the number of IARC personnel using the platform for their data storage and analysis, the number of projects stored on the SIT platform (folder storing data with an identified PI, data manager and user(s)), the number of hours of computing performed, and the number of terabytes stored and backed up on the SIT platform. Below are presented the key figures for 2022–2023, corresponding to the update on data science activities for the Scientific Council (SC) in February 2024.



KPIs for the project of the IARC Scientific IT platform. 52

<sup>52</sup> Source: Update on data science activities at IARC, SC/60/6, February 2024



# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

According to the MTS 2021-2025, "IARC stands as an open and neutral research platform. This position enables IARC to lead and significantly contribute to large scale international research consortia on cancer prevention... IARC houses data from international cancer research projects. IARC intends to enhance and facilitate the access of research communities around consortia to data and relevant analytical resources, including high performance computing. (...) These resources will be subject to responsible data management across the entire Agency's IT system, while ensuring compliance with applicable personal data security and data protection policies. Concurrently, IARC will foster a culture of enhanced cyber security while moving gradually to open data and cloud solutions".

→ The development of the SIT platform is perfectly in line with these objectives, although IARC chose to invest in its own infrastructure rather than using cloud solutions which are not compliant with the legal and technological constraints of the Agency.

# Integration into the IARC Project Tree

The Scientific IT platform is integrated into the IARC Project Tree under the following objectives:

#### Level 2 objective:

Objective 6. "Strengthening the efficiency and effectiveness of the Agency's research and collaboration."

#### Level 3 objectives:

Objective 6.1 "Ensure the availability of adequate laboratory and computing/statistical infrastructure to support and enhance research."

In addition, the SIT platform represents a major infrastructure for the research projects using large datasets and omics technologies, mainly related to the Level 2 Objective "Understanding the causes of cancer".

#### Achievements of assigned objectives

In 2023, the Agency defined its vision for open science explaining that "IARC commits itself to the advancement of science and the wide dissemination of knowledge to the benefit of society and cancer prevention, by adopting openness as one of its guiding principles. IARC acknowledges the necessity of balancing the desire for complete openness within scientific research with the need for restrictions where required, due to existing obligations around data protection, security, intellectual property rights, contractual obligations, legal restrictions and ethical considerations. IARC therefore aims to follow the principle of being "as open as possible, as closed as necessary", seeking to reconcile the ethos of Open Science with the complex realities of the research environment. Under this principle, any restrictions on openness are not the default but are exceptions based on justifiable obligations".

→ The IARC SIT platform provides access to shared centralized IT resources for scientific data storage and analysis, based on modern tools and best practices. It provides security and protection of data at every step of its life cycle and ensures continued access and dissemination of research data. It has been open to all IARC personnel since October 2021, after multiple testing phases. In that context, the SIT platform directly contributes to IARC's move into Open Science, specifically by developing a means to allow access to IARC-held data by third-party investigators remotely in a secure fashion. Those developments also addressed demands from various funding agencies that require IARC to share scientific data generated within funded projects to external investigators. In line with those principles, nearly 30 Data Use Agreements governing approximately 45 external users were signed in 2023–2024, to facilitate the implementation of projects on the SIT platform.



# Main challenges and future perspectives

#### Challenges

- The SIT platform has been financed from GCSF for the main investments, RB for staff and running costs, and some grants when available, for licenses and specific developments. However, according to DSSC members, this financing model does not provide continuity and makes investment planning difficult. To implement a sustainable SIT financing model development, they recommend gathering a lot of small fund inflows to cover the full cost of the SIT platform.
- The guiding principles for funding model of the SIT platform were defined as the following.
   IARC uses the SIT platform as a pilot project and intents to extend these principles to other
   IARC shared infrastructures (laboratories, biobank):
  - o "Cost allocation must be usage-based, fair and transparent,
  - Must be acceptable to the largest donors as direct costs,
  - Must allow for exceptions where the internal SIT user does not have direct funds, as this
    is a fundamental system used, and all internal users needing it will need to have access
    irrespective of financing,
  - o Must be implementable with budget and finance within the current system,
  - o Must be implementable to new funding applications,
  - Must finance at least a considerable proportion of the running costs of the SIT platform in a sustainable manner and should contain a possibility of extending the model to SIT investments or part of them in the future,
  - o Must include external participants / user fees,
  - Must take sustainability of Branches funding into consideration as well as the SIT platform budget".

#### **Perspectives**

- → The presentation shared during the SC meeting in February 2024 raises some interesting perspectives related to the development of the SIT platform. "As Artificial Intelligence and Machine Learning attract more and more attention in cancer research, an informal working group has been set up within IARC, to assess the interest of deep learning and other modern machine learning techniques for the analysis of data analysed at IARC. These methods are usually computationally intensive so their evaluation and application at IARC heavily relies on the SIT platform.
- → IARC scientists recently developed a new machine learning method, based on optimal transport, to automatically align untargeted metabolomics data acquired across multiple studies and illustrated its interest for the identification of metabolic biomarkers of alcohol intake using data from several untargeted metabolomics studies nested within the European Investigation into Cancer and Nutrition (EPIC) study.
- → The IARC working group recently initiated a project aimed at assessing the interest of auto-encoders and other non-linear unsupervised dimension reduction methods for the analysis of omics data, including transcriptomics and metabolomics data, in cancer epidemiology.
- → Deep learning is also transforming histopathological image analysis. IARC scientists have recently developed HaloAE (Mathian VISIGRAPP 2023), a local version of the Transformer architecture, known to achieve state-of-the-art performance in natural language processing (GPT-4), allowing for the first time its application on histopathological whole slide images".

#### For more details

- Update on data science activities at IARC #1
- Update on data science activities at IARC #2
- Report from the IARC
  working group on
  IARC/WHO vision for Open
  Science
- Request for support from the GCSF: Scientific IT platform



# Data protection Case study

# Implementation of the framework

During the current MTS period, IARC set up its data protection framework and implemented several steps to solidify it. In 2021, two external data protection consultants set up the data protection framework, conducted a comprehensive gap and impact analysis and wrote a report containing recommended measures to be taken to further solidify IARC's data protection framework. IARC established a comprehensive Register of Records of Data Processing Activities (ROPA) for all scientific and non-scientific data processed at IARC. The IARC Data Protection Policy, focusing on the

#### Summary

IARC has implemented a data protection framework that is in line with internationally recognized standards. This includes, without being limited to, the Personal Data Protection and Privacy Principles for UN System Organizations (the "UN Principles") adopted by the UN High-Level Committee on Management at its 36th Meeting on 11 October 2018, UN-HLCM 2018, and more specifically, the IARC Data Protection Policy. The IARC Data Protection Policy addresses the processing of personal data for scientific purposes by IARC personnel, as well as third parties collaborating with or acting on behalf of IARC. The Policy builds on the Personal Data Protection and Privacy Principles for UN System Organizations (UN-HLCM 2018) (the "UN Principles") as well as the WHO regulatory framework, and translates the principles enshrined in these documents to the specific framework at IARC. The principles referred to in the UN Principles are: Fair and legitimate processing, Purpose specification, Proportionality and necessity, Retention, Accuracy, Confidentiality, Security, The IARC Data Protection Policy was published in 2021 and is publicly available on the IARC website.

processing of personal data for scientific purposes, was finalized and published on IARC's public website. IARC worked closely with WHO to review and advise on the WHO's Data Protection Policy. The Agency has set up a Data Steward Network, in which appointed Data Stewards from each Branch take part, connecting science, data governance and IT. A Data Protection General Awareness training course was created, which will be is mandatory for all personnel as of 2022.

In 2022, IARC established a permanent Data Protection Officer position. IARC continued to strengthen its data protection framework to ensure alignment with internationally recognized standards. The IARC Data Protection Policy was shared with the Agency's collaborators, and the mandatory training in Data Protection General Awareness was rolled out and is a mandatory yearly exercise for all IARC personnel. Newcomers follow the training within their first month of arrival and receive a briefing for newcomers on data protection. IARC maintains the established comprehensive Register of Records of Data Processing Activities (ROPA) for all scientific and non-scientific data processed at IARC. IARC found solutions for data protection challenges within several scientific projects, ensuring that scientific collaborations can continue and data and samples can be shared with IARC. The Agency has worked on solutions that enable sharing data with collaborators remotely via the Scientific IT platform. These solutions have been set up in accordance with internationally recognized standards. The initial pilot phase has been successful.

In 2023, IARC updated and maintained the mandatory online Data Protection General Awareness training for all IARC personnel, to raise a good general level of awareness on data protection throughout the Agency. IARC continued to actively work on finding practical solutions for any arising data protection issues, including those related to data transfers. IARC has continued its collaborations with the European Commission, the European Data Protection Supervisor (EDPS), several networks of international organizations, and data protection authorities to work on long-term solutions to simplify data sharing with IARC. The IARC Data Protection Officer represented



IARC during the workshop on Data Protection for International Organizations held at INTERPOL organized by the EDPS and was a panel member for the topic "Data Transfers to and between International Organizations" and expressed concerns about the ongoing challenges, the strategy IARC has developed, and solutions found.

# **Structure**

#### Governance framework

The Data Protection and Legal Officer maintains the IARC Data Protection framework and ensures that data protection is taken into account within the organization as required to comply with internationally recognized data protection standards, negotiates all data/material transfer agreements, and is in close contact with WHO Legal and IARC's scientific collaborators about data protection matters to try to ensure that IARC's scientific projects can continue as planned.

#### **Links with WHO**

IARC closely collaborates with WHO on data protection, discusses challenges and solutions, shares contract templates and reviewed and provided advice on the WHO Data Protection Policy.

#### International collaborative network

IARC is in close contact with its scientific partners about data protection and is part of several networks of international organizations focusing on data protection, with other UN agencies and other international organizations. IARC is also part of several data protection working groups organized by the European Commission and the European Data Protection Supervisory. In addition, IARC collaborates where required with data protection authorities, such as the CNIL in France.

#### Resources

After the assignment on data protection run in 2021 by external consultants, the IARC resources for data protection consist of the Data Protection and Legal Officer. The investment in the Scientific IT platform also represents a contribution to the implementation of data protection for IARC and its partners.

# **Interface with other Pillars and Branches**

The IARC Data Protection and Legal Officer (DPO) closely collaborates with all Branches within IARC. The DPO reviews and negotiates all contracts related to access to or transfer of biospecimens and scientific data, such as Data Transfer Agreements (DTAs) or Material Transfer Agreements (MTAs). The table below shows the distribution of DTAs initiated in 2021–2023 for each IARC scientific Branch. The IARC DPO also works closely together with all Branches in any other project, working group, or context that needs input from a legal and data protection point of view, to ensure compliance with the IARC Data Protection Policy and data protection standards.

Data Transfer Agreements initiated in 2021-2023 per Branch				
Branch/year	2021	2022	2023	Total
CSU	2	25	9	36
GEM	14	29	57	100
NME	17	13	25	55
EGM	3	0	3	6
ENV	15	5	8	28
EPR	6	7	2	15
ESC	5	1	0	6
Total	62	80	104	246



# **Key Performance Indicators (KPIs)**

IARC's KPIs for data protection focus on the number of DTAs, as well as the number of MTAs for biological samples initiated and signed each year. During the current MTS period, the figures are as follows:

Year	Data Transfer Agreements		Material Transfer Agreements	
	Initiated	Signed	Initiated	Signed
2023	104	48	69	39
2022	80	53	43	29
2021	62	46	66	53
Total	246	147	178	121

The countries with which IARC has initiated the largest number of DTAs during the 2021–2023 period are USA (72 DTAs), UK (30 DTAs), France (21 DTAs), and Canada (20 DTAs). In addition to these DTAs and MTAs, the implementation of IARC's Scientific IT platform, with some pilot projects opening the platform for remote access by external collaborators in 2022 and 2023, led to the signature of 10 Data Use Agreements with external collaborators accessing the platform.

# **Alignment with IARC MTS 2021-2025**

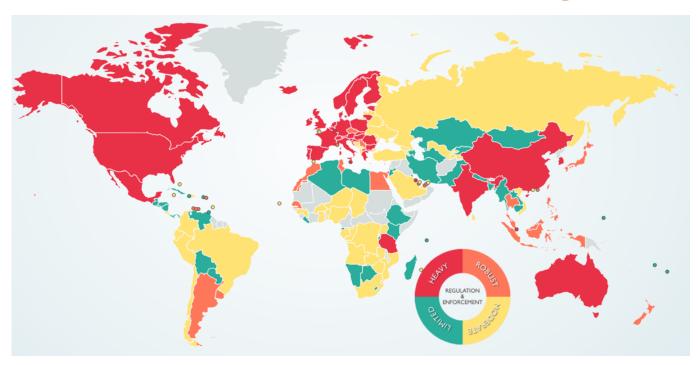
The MTS 2021-2025 clearly mentions the necessity for IARC to invest in scientific data and data security while complying with applicable data protection standards and other legal considerations: "IARC houses data from international cancer research projects. IARC intends to enhance and facilitate the access of research communities around consortia to data and relevant analytical resources, including high-performance computing. These resources will be subject to responsible data management across the entire Agency's IT system, while ensuring compliance with applicable personal data security and data protection policies" and "IARC will increasingly engage in open research data sharing..., while protecting the interests of IARC, its Participating States, and partners as well as the rights of individuals, including ethical and legal considerations.".

→ The IARC Data Protection Policy and the action plan implemented by the IARC Data Protection Officer directly contribute to this ambition and are perfectly in line with the IARC MTS 2021– 2025.

# Main challenges and future perspectives

As an international organization, part of WHO and the UN system, IARC is not subject to any national laws or regulations, including, without limitation, national/regional/federal data protection laws. IARC's scientific partners have to comply with their own legal frameworks, including national, regional, and federal data protection laws as applicable. When negotiating contracts for the transfer and processing of personal data to/from IARC, IARC tries to use its standard templates. The main challenge for IARC regarding data protection is the very strict interpretation by some collaborators of their data protection regulations and the lack of guidance they receive from their data protection authorities, resulting in constraints in sharing personal data and biospecimens for scientific projects with IARC. This challenge results in delays in some research projects or the need to change the initial plan of the project and IARC's role within some projects. So far, IARC has found solutions for these data protection challenges with many of its collaborators (e.g. with collaborators in Germany, the Netherlands, UK). The challenge is still the most present within IARC's collaborations with its partners in Scandinavia (e.g. within EPIC). The map below shows an overview of the data protection laws that are in place in 2024, at the international level:





Data protection laws around the world in 2024.53

- As shown in the KPIs on data protection, IARC is facing a growing number of required DTAs, MTAs, and DUAs to negotiate and sign each year. The numerous successes of IARC on grants directly contribute to the increase in the number of contracts required and therefore in the workload, because DTAs, MTAs, and DUAs have to be reviewed by and negotiated with each institution within these projects if data access/transfer is required. IARC continuously works on the template agreements and linked processes to streamline the process to limit the administrative burden. The IARC Data Protection Policy may require an update if the WHO Personal Data Protection Policy is adopted and officially published.
- A challenge that IARC scientists are facing concerns the required preparation of a data management plan (DMP) for some research projects, sometimes already within the grant application phase. Some major funders of IARC, such as NCI, INCa, and EC, require a DMP for a research project they fund from a data protection point of view; some standard text on how IARC is in principle handling data can be added to each DMP.
- Another challenge that IARC is facing is the lack of a metadata tool/software to track datasets held by IARC and all relevant metadata on that dataset. Such a tool is essential for proper data governance, tracking of contractual obligations, implementing the Open Science vision, and moving forward with opening the Scientific IT platform to external collaborators.

#### For more details

- → IARC Data Protection Policy
- → UN Personal Personal Data Protection and Privacy Principles
- → <u>Data protection laws in the</u> <u>world</u>



# Main conclusions and recommendations: outcomes



# Partnerships and international collaborations

IARC's publications demonstrate its global mandate, with 97% featuring international co-authorship. Of the top 25 countries for IARC co-publications, 88% are Participating States; the exceptions are Greece, Colombia, and South Africa. During the MTS period, IARC collaborated with partners from 123 countries, with significant ties to LMICs, which accounted for 24% of all collaborations and 50% of CRAs.

To better manage and strengthen these partnerships, IARC is encouraged to:

- Allocate resources and implement monitoring tools such as a CRM system integrated into the ongoing ERP project.
- → Although IARC has established collaborations with WHO headquarters, IAEA, and UICC, there is potential to enhance synergies with FAO on nutrition programmes and ILO on worker protection and occupational cancers.

#### **Capacity building**

IARC's contributions to capacity-building in cancer research are rooted in IARC flagship programmes such as the IARC Summer School, GICR, and GICRNet. These initiatives span the cancer research value chain; GICR plays a pivotal upstream role in sustaining cancer registries and feeding major programmes such as GLOBOCAN, Cancer Incidence in Five Continents (CI5), and SURVCAN, whereas the IARC Summer School disseminates IARC's research downstream. However, both the Summer School and the GICR face significant resource constraints that limit their ambitions.

→ The financial support for these programmes should reflect their importance to IARC's capacity-building efforts and overall activities.

# Dissemination and visibility

Dissemination is vital for IARC to achieve its mission. From 2021 to 2024, IARC's activities were featured in the press in 99 countries and on social media in 183 countries. A survey on policy impact identified 1403 IARC publications cited in 1915 policy documents, with 75% of these papers published before 2015, demonstrating the long-term impact of IARC's research on policy-making.

- → Although IARC has initiated qualitative assessments of its media and policy impact, further analysis at the programme level is needed to better understand its global influence.
- → IARC should also prioritize upgrading the Global Cancer Observatory (GCO) website as a central resource on cancer data, incorporating features such as expanded cancer surveillance tools (e.g. ChildCan) and new content on health economics and social inequalities.



#### **Open Science**

Open Science is a cornerstone of the IARC MTS. From 2021 to 2024, IARC has defined its Open Science vision, launched an open access biobank and Scientific IT platform, and implemented a data protection policy. The proportion of Open Access publications has grown substantially, reaching two thirds of IARC's scientific output in 2024. However, IARC has yet to join cOAlition S, unlike WHO and other leading organizations.

- → To fully realize its Open Science vision, IARC should continue investing in areas such as open research data, open-source software, open education, and citizen science, while also defining a sustainable financing model for the Scientific IT platform.
- → Agency-wide implementation of the data protection policy will further support these efforts.

# 4. MTS Impacts

→ The final category of KPIs for evaluating the MTS 2021-2025 measures the impacts of IARC's work, reflecting its long-term influence on global cancer control. These impacts include cooperation with WHO (4.1), impacts on prevention policies (4.2), impacts on clinical practices (4.3), and the economic and societal impacts (4.4).





# 4.1 Cooperation with WHO

# Impacts of the cooperation with WHO on implementation

Main ambitions of the MTS 2021-2025:

- Common strategy with WHO Headquarters NCDs Unit
- Support to WHO normative work
- Establishment of a formal engagement structure (IARC, WHO headquarters and regional offices)

#### KPIs:

- Joint strategic workplan/high-level oversight committee and implementation committee
- Contribution of IARC research to the three WHO global initiatives (case studies/co-authored publications) and Research Teams
- Contribution of IARC Handbooks to WHO guidelines (case study in prevention policies)

Source: ESC, CSU, PLW, ENV, EPR

A key ambition of the MTS 2021–2025 is sharing knowledge on cancer science with WHO to support guidance updates, promote best practices, and facilitate the implementation of national cancer programmes. IARC and WHO have complementary roles and mandates in advancing global cancer control.

In that regard, and as part of broader strategic activities, the IARC Statute places emphasis on cancer research, while WHO has the mandate in cancer control to support policy formulation and implementing programmes towards effective global cancer control. This pathway of research into policies and programmes is the basis for the complementary relationship between IARC and WHO. This cooperation of IARC with WHO headquarters consists of the definition and implementation of a joint strategic workplan, cooperation on national cancer control programmes with IAEA, IARC—WHO Standard Operating Procedure on the Monographs and Handbooks programmes, co-publications, and the collaborations on the three global cancer initiatives.

# Joint IARC-WHO headquarters strategic workplan

In 2022, IARC and WHO headquarters defined a strategic workplan for 2023–2025. This workplan proposes three core elements to further strengthen collaboration:

- 1. Creation of mechanisms to improve information sharing and knowledge, with a strong focus on the three WHO global cancer initiatives;
- 2. A set of priority projects co-designed between WHO and IARC to be implemented during the proposed workplan (GICR+, *IARC Handbooks* supplements, the Integrated Health Tool),
- 3. Committees for implementation, joint communication, and resource mobilization activities.

#### High-level oversight committee and implementation committee

The IARC-WHO headquarters strategic workplan for 2023–2025 defines the governance with three levels of coordination: Leadership Committee, Executive Committee, and Global Initiatives Team interface.

- IARC-WHO headquarters Leadership Committee: To promote areas of mutual cooperation and interest to WHO and IARC. The IARC-WHO headquarters Leadership Committee provides advice and guidance to the IARC-WHO headquarters Executive Committee on the ongoing development of joint activities within the workplan and reviews biannual reports. This may include additional areas of collaboration, engagement strategies with WHO headquarters partners, and/or resource mobilization activities.
- 2. IARC-WHO headquarters Executive Committee: To review progress on current activities, especially on the three co-designed projects, to identify and manage potential bottlenecks in collaboration, to track progress, and to report to the Leadership Committee.



3. Global Initiatives Cross-agency Working Group: Each of the global initiatives (Global Initiative for Childhood Cancer (GICC), Cervical Cancer Elimination Initiative (CCEI), Global Breast Cancer Initiative (GBCI), and Global Initiative for Cancer Registry Development (GICR)) holds regular meetings with participants from both organizations. The WHO Director of NCDs will designate focal points for each of its initiatives, and IARC has created cross-cutting Teams (as per the IARC MTS definition), alongside the existing GICR Team. They meet as a group on a regular basis to share information and knowledge and update each other on the latest developments. They explore possible avenues for collaboration, define coordinated activities with timelines and benchmarks, and inform the Executive Committee on recent activities, future needs, and opportunities, accordingly.

Furthermore, IARC-IAEA-WHO quarterly meetings were established form 2022 for Directors from IARC, IAEA, and the WHO headquarters Unit of Noncommunicable Diseases (NCDs), supported by the technical leads from each agency.

#### Cooperation on national cancer control programmes

IARC and its partners, WHO headquarters and IAEA, also contribute to the formulation of national cancer control programmes (NCCPs), which are vital for structured, sustainable cancer management within countries. The three agencies provide technical guidance and research data to help governments create effective NCCPs that prioritize cancer registration, prevention, early detection, and resource allocation. These programmes support countries in addressing cancer comprehensively, from risk factor control to early diagnosis and monitoring systems, helping to ensure a coordinated approach to cancer care.

Together, these three agencies form a powerful network to address global cancer challenges. By pooling their resources and expertise, they work to reduce the impact of cancer and promote sustainable cancer control strategies across diverse health-care systems worldwide. This triagency collaboration is essential in advancing cancer research, improving preventive measures, and ultimately saving lives globally.

#### IARC-WHO Standard Operating Procedure

In addition to these governance mechanisms established between IARC and WHO headquarters, a Standard Operating Procedure (SOP) was set up in 2018 between IARC and WHO headquarters to guide communication between the *IARC Monographs* and the *IARC Handbooks* programmes and WHO headquarters<sup>54</sup>. This SOP can be used as a reference for communication of other programmes of mutual interest.

In 2022, it was agreed by the IARC Governing Council that the SOP would be updated through 2023–2024 based on the 6-year experience gained in its application and on consultation with WHO headquarters. During this period, the IARC Secretariat has worked in full consultation with WHO headquarters on a revised version of the SOP, to optimize coordination and communication processes between IARC and WHO headquarters. The updated SOP, as agreed upon by both IARC and WHO headquarters, will be finalized in early 2025. The agreed-upon updated draft SOP will be presented at the Sixty-seventh session of the IARC Governing Council in May 2025.

 $<sup>^{54}</sup>$  https://events.iarc.who.int/event/46/attachments/110/483/GC60\_13\_CoordinationWHO.pdf and https://events.iarc.who.int/event/46/attachments/110/484/GC60\_13\_Corr1.pdf



#### IARC co-publications with WHO headquarters

IARC's support to WHO normative work has been demonstrated in a substantial number of coauthored scientific publications, as reported below for the MTS period.

#### IARC-WHO co-publications in 2021:

- Duggan C et al. National health system characteristics, breast cancer stage at diagnosis, and breast cancer mortality: a population-based analysis. Lancet Oncol. 22:1632–1642, 2021.
- Stelzle D et al. Estimates of the global burden of cervical cancer associated with HIV. Lancet Glob Health, 9:e161-e169, 2021.
- Bray F et al. Comparing cancer and cardiovascular disease trends in 20 middle- or high-income countries 2000-19: a pointer to national trajectories towards achieving Sustainable Development Goal Target 3.4. Cancer Treat Rev, 100:102290, 2021.
- Johnson S et al. The World Cancer Declaration: time to consolidate wins and work towards 2025. Lancet Oncol, 22(3):296–298, 2021.

#### IARC-WHO co-publications in 2022:

- IARC (2022). Cervical cancer screening. IARC Handbook of Cancer Prevention 18:1–456. Available from: https://publications.iarc.fr/604.
- Guida F et al. Global and regional estimates of orphans attributed to maternal cancer mortality in 2020. Nat Med, 28, 2563–2572, 2022.
- Khalili AI et al. Age-specific burden of cervical cancer associated with HIV: a global analysis with a focus on sub-Saharan Africa. Int J Cancer, 150:761–772, 2022.

#### IARC-WHO co-publications in 2023:

- IARC; Department of Health and Health Service Executive of Ireland (2023). Best practices in cervical screening programmes: audit of cancers, legal and ethical frameworks, communication, and workforce competencies. Lyon, France: International Agency for Research on Cancer (IARC Working Group Reports, No. 11). Available from: https://publications.iarc.fr/625.
- El Amine Youcef Ali M et al. Inequities in cancer outcomes. Bull World Health Organ, 101:550, 2023.
- Pega F et al. Global, regional and national burdens of non-melanoma skin cancer attributable to occupational exposure to solar ultraviolet radiation for 183 countries, 2000–2019: a systematic analysis from the WHO/ILO Joint Estimates of the Work-related Burden of Disease and Injury. Environment International, 181, 2023.
- Oral Cancer Prevention: *IARC Handbooks of Cancer Prevention* Volume 19, 2023. Available from: https://publications.iarc.who.int/617.
- 1st edition of the Latin America and the Caribbean Code Against Cancer, 2023. Available from: https://cancer-code-lac.iarc.who.int/en/.

#### IARC-WHO co-publications in 2024:

- WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention: use of dual-stain cytology to triage women after a positive test for human papillomavirus (HPV), 2024.
- Simba H et al. Impact of cancer across the intergenerational family: a multidimensional perspective from African countries. JCO Glob Oncol, 2024
- Mosquera I et al. (2024). Assessment of barriers and interventions to improve cancer screening programmes in Latin American and Caribbean countries: outcomes of the CanScreen5/CELAC project. Lyon, France: International Agency for Research on Cancer. Available from: https://publications.iarc.who.int/639. Licence: CC BY-NC-ND 3.0 IGO.



#### Contribution of IARC research to the three WHO headquarters global cancer initiatives

IARC research informs the goals of the WHO headquarters global cancer initiatives (Global Cervical Cancer Elimination Initiative, Global Breast Cancer Initiative, Global Initiative for Childhood Cancer, Global Initiative for Cancer Registry Development) and is vital for monitoring progress towards attaining the targets. The findings of scientists from IARC and partner institutions also provide the evidence base for WHO recommendations. For example, the framework for the WHO Global Breast Cancer Initiative has KPIs informed by the IARC-led research in sub-Saharan Africa. In cervical cancer, examples are the recent update to WHO recommendations on the HPV vaccination schedule and the updated WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention.

IARC's contribution to the three global cancer initiatives is facilitated through three dedicated IARC Research Teams, established in 2023. These Teams aim to enhance information sharing, knowledge dissemination, and coordination with the WHO Cancer Team, aligning closely with the objectives of the WHO global initiatives on breast, cervical, and childhood cancers. The three IARC Research Teams are:

- → IARC Research Team on breast cancer related to the WHO Global Breast Cancer Initiative
- → IARC Research Team on cervical cancer related to the WHO Cervical Cancer Elimination Initiative
- → IARC Research Team on childhood cancer related to the WHO Global Initiative for Childhood Cancer.

The benefits of these three IARC Research Teams are:

- A more structured approach and dialogue with WHO about the three WHO global cancer initiatives. These IARC Research Teams bring together all IARC projects specifically related to the respective WHO initiatives and dedicated staff members.
- Improved coordination with WHO: each IARC Research Team is coordinated by a Team leader, who is the IARC focal point for WHO, and includes a staff member to take minutes, action points and follow-up, and to convene regular internal and IARC-WHO meetings.
- Greater visibility for IARC on its research on these three cancers related to the WHO initiatives, through the development of dedicated websites.

Table 35 reports the number of IARC publications on breast, cervical, and childhood cancers from January 2021 to November 2024, along with the percentage of IARC publications directly contributing to the three WHO global cancer initiatives.



Table 35. Number and evolution of IARC publications of IARC related to the WHO global cancer initiatives on cancer since 2021<sup>55</sup>

	2021	2022	2023	2024
WHO Global Breast Cancer	23 IARC publications on breast cancer	22 IARC publications on breast cancer	36 IARC publications on breast cancer	21 IARC publications on breast cancer
Initiative (IARC Branches: CSU, EPR, ENV, ESC)	8 publications related to the WHO Global Breast Cancer Initiative (35%)	10 publications related to the WHO Global Breast Cancer Initiative (45%)	19 publications related to the WHO Global Breast Cancer Initiative (53%)	11 publications related to the WHO Global Breast Cancer Initiative (52%)
WHO Cervical Cancer Elimination Initiative  (IARC Branches: CSU, EPR, ESC)	10 IARC publications on cervical cancer 9 publications related to the WHO Cervical Cancer Elimination Initiative (90%)	14 IARC publications on cervical cancer 14 publications related to the WHO Cervical Cancer Elimination Initiative (100%)	30 IARC publications on cervical cancer 28 publications related to the WHO Cervical Cancer Elimination Initiative (93%)	13 IARC publications on cervical cancer 13 publications related to the WHO Cervical Cancer Elimination Initiative (100%)
WHO Global Initiative for Childhood Cancer (GICC)	6 IARC publications on childhood cancer 3 publications related to the WHO Global	10 IARC publications on childhood cancer 5 publications related to the WHO Global	7 IARC publications on childhood cancer 4 publications related to the WHO Global	7 IARC publications on childhood cancer 5 publications related to the WHO Global
(IARC Branches: CSU, ENV, ESC)	Initiative for Childhood Cancer (50%)	Initiative for Childhood Cancer (50%)	Initiative for Childhood Cancer (57%)	Initiative for Childhood Cancer (71%)

<sup>55</sup> Source: IARC, DIR Office and SSR (PLW), November 2024.

# Childhood Cancer Awareness and Research Evidence (CCARE) Team

#### **Members**

**Team leaders:** Dr Eva Steliarova-Foucher, Cancer Surveillance Branch (Scientist, CSU) and Dr Akram Ghantous, Epigenomics and Mechanisms Branch (Scientist, EGM) – Secretary: Dr Neimar de Paula Silva (Postdoctoral Scientist, CSU)

**Team members:** The Team comprises 21 team members from 6 Branches (CSU, NME, ENV, EGM, EPR and ESC, with support from the Director's Office.

→ Dr Véronique Chajès (DIR); Mr Clément Chauvet (DIR); Senior advisors: Dr Freddie Bray (Branch Head, CSU), Dr Joachim Schüz (Branch Head, ENV), Dr Zdenko Herceg (Branch Head, EGM) and Dr Mary Schubauer-Berigan, (Branch Head, ESC). Members: Dr Ceren Süngüc (Postdoctoral Scientist, CSU); Dr Inge Huybrechts (Scientist, NME); Dr Shiny Manohar (IARC Postdoctoral Fellow, NME); Dr Zisis Kozlakidis (Scientist, Laboratory Support, Biobanking and Services [LSB]/NME); Dr Andre Carvalho (Scientist, EPR); Dr Ann Olsson (Scientist, ENV); Dr Ljubica Zupunski (Scientist, ENV); Dr Michele Matta (Scientist, ENV); Dr Rita Khoueiry (Scientist, EGM); Dr Farah Nassar (Postdoctoral Scientist, EGM); Dr Elisa Pasqual (ESC); Ms Véronique Terrasse (COM).

# Cancer types Teams → Starting date: March 2023

#### **Objectives**

#### Context

Each year, nearly 400 000 children aged 0-19 years develop cancer, and about 90% of these cases occur in LMICs. Whereas children in high-income countries have a more than 80% chance of surviving cancer with optimal care, survival rates for those in LMICs tragically range from only 15% to 45%. In response to this critical situation, WHO launched the Global Initiative for Childhood Cancer (GICC) in September 2018, in collaboration with St. Jude Children's Research Hospital in the USA. The GICC aims to achieve a global survival rate of at least 60% for children with cancer while ensuring reduced suffering for every child. Using the "CureAll" framework, the GICC coordinates stakeholders across sectors toward common objective.

The GICC has two key objectives:



- 1. Capacity building: To enhance the ability of countries to provide high-quality information and services for children with cancer.
- 2. Prioritization of childhood cancer: To elevate the importance of childhood cancer on global and national agendas.

Launched in March 2023, the WHO-IARC Team on childhood cancer aims to improve information sharing and dialogue between IARC and the GICC team at WHO headquarters. The CCARE Team's ambition is to leverage ongoing research at IARC, foster coherent collaboration with WHO headquarters in support of the GICC, translate research findings into actionable strategies, and identify synergistic areas of work.

To achieve these objectives, the team members engage in regular meetings, both internally within IARC and with WHO partners. The specific goals of the CCARE Team include:

- Enhancing internal communication and identifying synergies in childhood cancer research.
- Streamlining the dissemination of knowledge generated by IARC on childhood cancer.
- Supporting the WHO GICC by providing scientific evidence to inform global actions.



Goal	By 2030, achieve at least 60% survival for childhood cancer globally and reduce suffering for all				
0	Save one million additional lives				
Objectives	<ol> <li>Increase capacity of countries to provide quality services for children with cancer, and</li> <li>Increase prioritization of childhood cancer at the global, regional and national levels</li> <li>Implemented across 6–10 countries (by 2019–2020) and 18–25 countries (by 2021–2023)</li> </ol>				
	National	Regional	Global		
Outputs & activities	Country assessment, case studies, support and implementation plans	Regional assessment and dialogues, snapshots and policy briefs	Global framework, technical package, dashboard and advocacy materials		

#### Workplan progress

#### Projects and consortia

The CCARE Team is engaged in several key projects aimed at enhancing knowledge and improving outcomes for childhood cancer globally. Key initiatives include:

- International Incidence of Childhood Cancer (IICC): This project processes and disseminates data from population-based cancer registries worldwide, creating a unique resource on childhood cancer incidence. The latest volume (IICC-3) was supported by the Union for International Cancer Control (UICC).
- International Classification of Childhood Cancer (ICCC): A standardized system categorizing
  paediatric cancer types according to WHO guidelines, facilitating consistent reporting of
  childhood cancer statistics globally.
- Childhood Cancer Registration Development (ChildGICR): This initiative focuses on enhancing childhood cancer registration in LMICs through educational programmes and implementation research, in collaboration with St. Jude Children's Research Hospital.
- Cancer Risk in Childhood Cancer Survivors (CRICCS): Using quality-assured data from cancer registries, this project aims to estimate the number of childhood cancer survivors, assess their risk of second cancers, and develop guidelines for studying survivorship.
- Childhood Cancer and Leukaemia International Consortium (CLIC): A collaborative effort among more than 20 studies investigating the etiology of childhood cancer, particularly environmental causes, with a focus on leukaemia. CLIC is expanding its scope to include childhood brain tumors.
- Childhood Cancer Epidemiology, Research, and Omics (CICERO): This multidisciplinary
  project investigates childhood cancer in Africa, focusing on ascertainment completeness,
  referral patterns, survival, and treatment completion, while also defining molecular profiles of
  cases.
- CIRE-RF Study: A registry-based case-control study examining the association between childhood cancer and exposure to radiofrequency electromagnetic fields.
- Childhood Leukaemia and Environmental Risk Factors (CLERF): A pilot study in Germany
  investigating the feasibility of recruiting patients with leukaemia for etiological research on
  gene-environment interactions.



#### Governance

#### Meetings:

- The preparatory meeting for the CCARE Team was held on 25 January 2023.
- Since its formation, the Team has convened four meetings during 2023-2024, adopting the name CCARE in July 2024.
- The Team meets on average once a quarter.
- In addition to these regular meetings, smaller technical meetings are frequently held for organizational and communication purposes among the co-leaders.
- Minutes of the meetings and all relevant documents are stored in the Team channel for easy access.

#### Collaboration with WHO

- The CCARE Team has established a close partnership with WHO headquarters to ensure effective coordination for the Global Initiative for Childhood Cancer (GICC).
- Team members have participated in 11
  preparatory meetings for the Global Status
  Report and 4 special meetings with WHO
  headquarters to discuss childhood cancer.

- COVID-19 and Childhood Cancer: This project evaluates the impact of the COVID-19 pandemic on childhood cancer incidence, referral, diagnosis, and treatment.
- EPiChildCan: A project focused on identifying epigenetic precursor markers associated with early-life factors and childhood cancer risk, leveraging large networks of prospective and retrospective studies.
- International Lifestyle Behaviour and Biobanking Programme in Paediatric Oncology: A collaboration aimed at developing resources to study the impact of nutrition and lifestyle factors on health outcomes in children with cancer.
- Global Acute Leukaemia/Lymphoma Network (GALnet): This consortium enhances collaboration between high-income and lowincome countries in paediatric oncology, contributing to improved detection and treatment.
- Determinants of Late Diagnosis and Delayed Treatment of Cancer (DEDICA): A study evaluating the factors affecting timely diagnosis and treatment initiation in childhood cancers.
- *IARC Monographs* Programme: Identifying causes of human cancer, including childhood cancers, and evaluating agents associated with cancer risk.
- South-ROCK: An integrated center of excellence in paediatric oncology research based in southern France, focusing on therapeutic strategies and environmental factors in cancer prevention.

#### Applications and grants

Since its establishment, the CCARE Team has successfully secured several grants, totalling more than €1.3 million, including:

- **EpiEarlyCNS**: Funded by the French National Cancer Institute, focusing on epigenomic analyses of paediatric brain cancer.
- WpCigCAD: A project investigating the molecular effects of tobacco across life stages.
- ENV-ALL: Examining maternal exposure to environmental hazards and its link to acute lymphoblastic leukaemia.
- CICERO: Funded by the Dutch Ministry, focusing on childhood cancer in Africa.
- ChildGICR: A collaborative programme with St Jude for childhood cancer registration.
- pLeuk.Fol.WCRF: Investigating the role of maternal folate's role in childhood leukaemia initiation.

#### Training

The CCARE Team prioritizes training, with several initiatives including:

- Online courses: Training on childhood cancer registration conducted in collaboration with health organizations in Georgia and Trinidad and Tobago.
- IARC seminar: Plans for seminar in early 2025 dedicated to childhood cancer research at IARC.
- Supervision and training: Ongoing supervision of postdoctoral scientists involved in childhood cancer research.



#### **Key partners**

#### Cooperations across IARC Branches

The CCARE Team collaborates on various publications and projects across different IARC scientific branches:

- NME, CSU, and LSB: Publications focusing on early-life nutrition and its relationship to childhood cancer.
- CSU and ENV: Collaborative works on childhood cancer incidence statistics.
- ENV, EGM, and CSU: The CICERO project: Childhood Cancer Epidemiology, Research, and Omics, funded by the Ministry of Health, Welfare and Sports of the Netherlands.
- **EGM and ENV**: Projects exploring the origins and causes of paediatric cancer (PEDIAC and PEDIAHRG).
- EGM and CSU: South-ROCK project—Research on Cancer in Kids, funded by INCa, France.
- Collaboration with WHO for a side event focused on nutrition and childhood cancer and contributions to the Global Status Report on Cancer.

#### Collaboration with external partners

- The CCARE Team participates in significant events such as the International Childhood Cancer Day (celebrated since 2003) on 15 February and Childhood Cancer Awareness Month in September (in 2023 and 2024).
- Collaborations extend to numerous organizations, including:
  - Union for International Cancer Control (UICC)
  - o Government of the Netherlands
  - French National Cancer Institute (INCa)
  - o St. Jude Children's Research Hospital (USA)
  - o Children with Cancer UK
  - o International Childhood Cancer Cohort Consortium (I4C)
  - o Childhood Leukemia International Consortium (CLIC)
  - o Pregnancy and Childhood Epigenetics Consortium (PACE)
  - o Cancer Research Center of Lyon (CRCL)
  - SEER/NCI

#### **Main innovations**



- Global childhood cancer registration: Development of a standardized system for childhood cancer registration, enhancing data collection and analysis globally.
- International initiative for paediatrics and nutrition: Investigating the influence of diet, obesity, and metabolic health on childhood cancer, particularly in LMICs.
- Environmental risk factors: Studying links between exposure to magnetic fields from power lines and childhood leukaemia, as well as parental pesticide exposure.
- Molecular causes of childhood cancer: Exploring the effects of maternal and paternal age, adiposity during pregnancy, and lifestyle factors on cancer risk in children.
- Indicators of cancer burden: Developing indicators tailored for childhood populations to assess the global burden of childhood cancer.
- **Economic impact analysis:** Evaluating the financial impact of childhood cancer on families in LMICs.

### **Contributions to MTS implementation**

The CCARE Team's activities align with the MTS 2021–2025, contributing to: **Fundamental priorities:** 

- → Data for action: Collection and analysis of childhood cancer incidence and survival data.
- → Understanding causes: Investigating epidemiological and molecular risk factors.



- > From understanding to prevention: Identifying biomarkers for early detection.
- → Knowledge mobilization: Supporting research and capacity building in LMICs.

#### **Emerging priorities:**

- → Evolving cancer risk factors: Addressing childhood cancer research in LMIC populations.
- → Implementation research: Assisting WHO's GICC in reducing the childhood cancer burden.

#### Main challenges

- **Diverse research themes:** The wide scope of research makes it challenging to produce comprehensive grant applications and publications.
- **Need for data management**: Developing reliable data management strategies and trusted collaborations with data providers is essential for effective research.
- Funding and sustainability: The Team faces challenges in securing long-term funding and maintaining momentum in its initiatives.

#### **Next steps**

To advance its objectives, the CCARE Team plans to:

- → Communication campaign: Launch a campaign in September 2024 to highlight childhood cancer research, with a dedicated webpage to showcase activities and results.
- → Support GICC: Develop an action plan to assist with the Global Status Report, ensuring effective communication of IARC's contributions.
- → Stimulate scientific exchange: Organize an IARC seminar on childhood cancer and foster collaborative publications.
- → Implementation support: Create lay publications, evidence summaries, and training courses tailored for a general audience.
- → Resource mobilization: Actively seek funding opportunities and collaborate with IARC's Resource Mobilization Office.

#### **RECOMMENDATIONS**



The CCARE Team should focus on:

- Proposing methods for managing and disseminating data tailored to sparse information environments.
- Concentrating on research projects that explore poorly understood risk factors, crucial for developing prevention programmes.
- ✓ Strengthening collaboration with WHO and supporting GICC by leveraging the expertise across all IARC pillars (1, 2, 3, and 4).

### **Key publications**

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- Onyije, F. M., R. Dolatkhah, A. Olsson, L. Bouaoun, and J. Schüz. <u>Environmental risk factors of Wilms tumour: a systematic review and meta-analysis.</u> European Journal of Cancer: Paediatric Oncology 4, 100178 (Dec 2024).



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- Li, S., N. Spitz, A. Ghantous, S. Abrishamcar, B. Reimann, I. Marques, et al. <u>A Pregnancy and Childhood Epigenetics Consortium (PACE) meta-analysis highlights potential relationships between birth order and neonatal blood DNA methylation.</u> Commun Biol 7, no. 1 (Jan 9 2024): 66.
- Bosch de Basea Gomez, M., I. Thierry-Chef, R. Harbron, M. Hauptmann, G. Byrnes, M. O. Bernier, et al. <u>Risk of hematological malignancies from CT radiation exposure in children.</u> <u>adolescents and young adults</u>. Nat Med 29, no. 12 (Dec 2023): 3111-19.
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   IARC International Incidence of Childhood Cancer (IICC)
- Childhood Cancer and Leukemia International Consortium (CLIC)
- Global Acute Leukaemia network (GALnet)
- Targeting childhood cancer through Global Initiative for Cancer Registry development ChildGICR
- Cancer Risk in Childhood Cancer Survivors (CRICCS)
- EpiChildCan project
- WHO Classification of Tumours Paediatric tumours
- WHO Global Initiative for Childhood Cancer

# IARC Cervical Cancer Elimination Initiative (CCEI) Team

#### **Members**

**Team leaders**: Dr Mary Luz Rol (Scientist and Team leader, EPR) and Dr Partha Basu (Branch Head and co-Team leader; EPR)

**10 team members** from 4 Branches in Pillars 1, 3 and 4:

→ Dr Freddie Bray (Branch Head; CSU); Dr Ariana Znaor (Scientist; CSU); Dr Gary Clifford (Deputy Head; EPR); Mr Eric Lucas (Scientist; EPR); Dr Iacopo Baussano (Scientist; EPR); Dr Tatiana Ramirez (Postdoctoral Scientist; EPR); Dr Tarik Gheit (Scientist, EGM) invited to participate as member, September 2024); Dr Gabrielle Goldman Levy (Pathologist; ESC); Mrs Anouk Berger (Branch Head; LCB)



Cancer types Teams
→ Starting date: April 2023

#### **Objectives**

#### Context

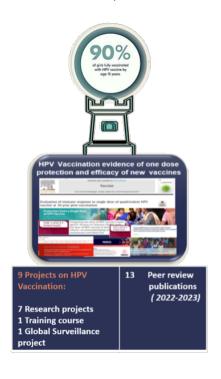
Cervical cancer primarily results from persistent infection with high-risk types of human papillomavirus (HPV), a highly prevalent virus transmitted through sexual contact. Although cervical cancer is one of the most preventable and treatable cancers, an estimated 604 000 women were diagnosed globally in 2020, resulting in about 342 000 deaths, and 90% of cases and deaths occurred in LMICs.

In November 2020, WHO launched the Global Strategy to Accelerate the Elimination of Cervical

Cancer. This strategy is built on three strategic pillars with specific targets:

- → Vaccination: 90% of girls fully vaccinated with the HPV vaccine by age 15 years.
- → Screening: 70% of women screened with a high-performance test by ages 35 and 45 years.
- → Treatment: 90% of women with precancer treated and 90% of women with invasive cancer managed.

To achieve these 90–70–90 targets by 2030, IARC supports the WHO initiative by providing crucial evidence, technical materials, and updates for policymakers and programme managers.









The IARC CCEI Team was established to enhance communication and coordination with the WHO Cancer Team and to facilitate knowledge and expertise exchange related to the CCEI. The primary goal of the IARC CCEI Team is to foster collaboration among CCEI partners, including WHO, while sharing scientific evidence and updates on relevant IARC initiatives and publications.



#### Research focus

IARC Team members are conducting research in three key areas within the CCEI framework. The CCEI Team's workplan includes:

- → Studying immune responses to and effectiveness of one dose of the HPV vaccine compared with two and three doses.
- → Evaluating the feasibility and effectiveness of various cervical cancer screening methods.
- Assessing the safety and effectiveness of novel precancer treatment methods and evaluating real-world effectiveness through implementation research.

#### Workplan progress

#### Projects and consortia

The CCEI Team manages 41 ongoing research and capacity-building projects, categorized as follows:

- 9 projects related to vaccination
- 21 projects related to screening
- 11 projects related to treatment and cancer incidence

#### Applications and grants

The CCEI Team has successfully secured the following grants:

HPV Vaccine Effectiveness Coordination
 Center

Funder: Bill & Melinda Gates Foundation IARC Budget: €4,299,652 (Direct funding) IARC PI: Dr Iacopo Baussano (Coordinator)

#### Governance

The CCEI Team meets regularly to coordinate efforts, discuss priorities, and strategize grant applications. Team members also serve on steering committees for various collaborative projects at IARC focused on cervical cancer prevention.

#### Links with WHO

The CCEI Team collaborates closely with WHO, specifically with Dr Bente Mikkelsen, the Director of the Noncommunicable Diseases Division at WHO headquarters. This partnership extends to WHO regional offices, including those of the Americas (PAHO), Africa (AFRO), and South-East Asia (SEARO). To support this collaboration, the CCEI Team has shared a comprehensive database of 41 IARC projects with WHO, accompanied by summary presentations of each project. These initiatives are also featured in the WHO Cervical Cancer Elimination Initiative Knowledge Repository.

The CCEI Team actively participates in various WHO CCEI activities and events, including:

- The commemoration on 17 November 2023.
- The CCEI stakeholder online meeting on 4 December 2023.
- The CCEI stakeholder meeting in Cartagena, Colombia, on 5–8 March 2024.

Furthermore, the CCEI Team contributes to training programmes for the WHO Academy. A massive hybrid learning programme on cervical screening and management, developed with technical support from IARC, is set for release by the end of 2024.

Measurement of Human Papillomavirus (HPV) Vaccine Introduction Impact

Funder: WHO headquarters

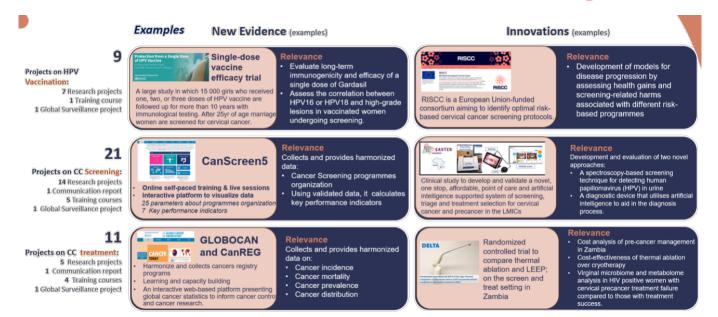
IARC Budget: €1,295,072 (Direct funding) IARC PI: Dr Iacopo Baussano (Partner)

 HPV Self-Sampling in the General Population: Efficacy, Feasibility, Acceptability, and Cost-Effectiveness (MIRABELLE)

Funder: Institut National du Cancer (INCa FR) IARC Budget: €400,246 (Regular grant) IARC PI: Dr Catherine Sauvaget (Coordinator)

In addition to these three grants, two applications are currently under review by the European Commission (project HPV FASTER IMPLEMENT) and NIH (HPV circulating DNA as a pre-diagnostic marker for anal and other HPV-related cancers in individuals living with HIV).

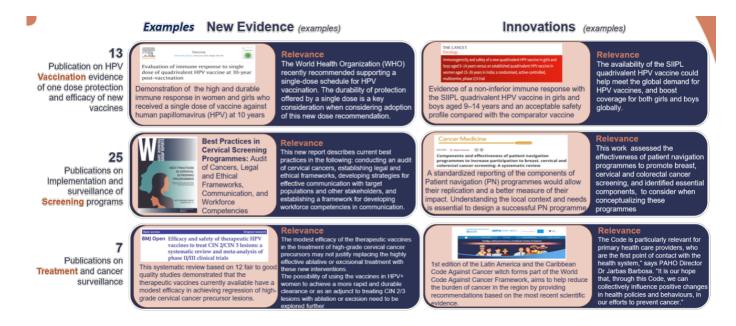




#### **Publications**

The CCEI Team has produced 45 publications on HPV and cervical cancer (see "Key publications" below), including:

- 13 on HPV vaccination
- 25 on screening programmes
- 7 on treatment and cancer surveillance.



#### **Training**

The CCEI Team is developing extensive training materials on cervical cancer, including the HPV atlas to support cervical cancer elimination (see "References" below) and presentations for the IARC Summer School. The Team collaborates with the International Federation for Cervical Pathology and Colposcopy (IFCPC) on training initiatives. Notably, Team members contributed to one of the first courses offered by the WHO Academy in 2020: "Comprehensive Learning Programme on Screening, Diagnosis, and Management of Cervical Precancer".



#### **Main innovations**

One significant strength of the CCEI Team is its ability to leverage extensive data from LMICs to create relevant models that are not solely based on perspectives from HICs. This approach aids WHO in defining meaningful targets and clear messages for governments in LMICs.

Key innovations from the CCEI Team include:

- Single-dose HPV vaccine study: An important IARC study demonstrating that a single dose of the HPV vaccine provides adequate protection against the virus, with high immunogenicity persisting for at least 10 years. Based on these findings, WHO recently recommended the adoption of a single-dose vaccination schedule.
- Cervical cancer screening evaluation: The CCEI Team is evaluating the feasibility and effectiveness of various cervical cancer screening methods. The IARC Handbooks of Cancer Prevention Volume 18: Cervical Cancer Screening was published in May 2022.
- Performance assessment of VIA: A recent IARC study assessed the performance of visual inspection of the cervix with acetic acid (VIA), a low-cost screening method, and evaluated the ability of VIA

providers to determine eligibility for ablative treatment.

#### **Key collaborations**

Collaborations across Branches
Under the leadership of the EPR Branch in Pillar 3, the CCEI Team collaborates with Pillar 1 (CSU) for cervical cancer data, as well as Pillar 3 (ESC and LCB). The CCEI Team has worked with the ESC Branch on the IARC Handbooks programme (Handbook on Cervical Cancer Screening) and the Blue Books programme (WHO Classification of Tumours: Female Genital Tumours). In addition, the Team is heavily involved in training programmes and collaborates closely with the LCB Branch.

External collaborations
In addition to WHO, key partners for the CCEI Team include the Bill & Melinda Gates Foundation (BMGF), the United States National Cancer Institute (NCI/NIH), and the European Commission. BMGF provides significant funding for several of the CCEI Team's projects, totalling several million US dollars (see Workplan progress on projects and grants).

### **Contributions to MTS implementation**

IARC's contributions to the WHO Global Strategy to Accelerate the Elimination of Cervical Cancer are prioritized in the MTS 2021–2025, stating that "IARC contributes to the implementation of the WHO Global Strategy to Accelerate the Elimination of Cervical Cancer as a Public Health Problem through r e-evaluating the effectiveness of cervical cancer screening; monitoring and evaluating cervical cancer elimination in sub-Saharan Africa; assessing HPV vaccination interventions in various countries; and evaluating the effectiveness of cervical cancer screening and treatment programmes for precancerous lesions. Over the next five years, IARC will assess the efficacy and effectiveness of HPV vaccination programmes (including reduced dosing schedules) in diverse implementation scenarios. The generated evidence will support health authorities in deploying mass HPV vaccination initiatives."

#### Fundamental priorities

The workplan of the CCEI Team directly addresses three fundamental priorities of the MTS 2021-2025:

- → Data for action: Providing estimates of cervical cancer incidence and mortality and maintaining the CCEI Knowledge Repository.
- → From understanding to prevention: Conducting projects on HPV vaccination and implementation research on screening and treatment.
- → Knowledge mobilization: Developing the IARC Handbooks of Cancer Prevention volume on Cervical Cancer Screening, the Atlas on cervical cancer, and training materials, including courses for the WHO Academy.





#### **Main challenges**

According to the CCEI Team leaders, the primary challenges for the CCEI Team include:

- Communication: Ensuring regular communication with the WHO NCD department and maintaining centralized communication with WHO.
- Resource mobilization: Securing funding to support IARC's participation in CCEI events.

### **Next steps**

The CCEI Team identifies the following next steps for developing the CCEI Team:

- Continue coordinating internal communication on CCEI within IARC.
- → Work on defining IARC's vision for the CCEI.
- → Maintain active participation in WHO activities related to the CCEI

### **RECOMMENDATIONS**



- ✓ The scientific output of the CCEI Team provides an excellent foundation for developing models and cost-benefit analyses of cancer prevention programmes. Projects led by Dr Iacopo Baussano, supported by CSU data, should enable IARC to pursue new ambitions in health economics, using cervical cancer as a pilot project.
- ✓ The CCEI Team exemplifies effective collaboration with WHO on the initiative to eliminate cervical cancer. In March 2024, WHO announced significant investments in CCEI, amounting to a US\$ 600 million budget. This funding includes US\$ 400 million from the World Bank, US\$ 180 million from the Bill & Melinda Gates Foundation, and US\$ 10 million from UNICEF. The CCEI Team should establish the appropriate interface with WHO in light of this new ambition.



#### **Key publications**

#### Key publications on HPV vaccination:

- Joshi S, Anantharaman D, Muwonge R, Bhatla N, Panicker G, Butt J, et al. (2023). <u>Evaluation of immune response to single dose of quadrivalent HPV vaccine at 10-year post-vaccination</u>.
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- IARC; Department of Health and Health Service Executive of Ireland (2023). <u>Best practices in cervical screening programmes: audit of cancers, legal and ethical frameworks, communication, and workforce competencies.</u> Lyon, France: International Agency for Research on Cancer (IARC Working Group Reports, No. 11). Licence: CC BY-NC-ND 3.0 IGO.
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   Consortium (2023). Survey of current policies towards widening cervical screening coverage among vulnerable women in 22 European countries. Eur J Public Health. 33(3):502–8.

#### Cervical cancer treatment and surveillance:

- WHO Classification of Tumours Editorial Board (2020). <u>Female genital tumours. 5th ed.</u> Lyon, France: International Agency for Research on Cancer (WHO Classification of Tumours series, Vol. 4).
- IARC and PAHO (2023). <u>Latin America and the Caribbean Code Against Cancer. 1st ed.</u> Lyon, France: International Agency for Research on Cancer; Washington (DC), USA: Pan American Health Organization.
- Singh D, Vignat J, Lorenzoni V, Eslahi M, Ginsburg O, Lauby-Secretan B, et al. (2023). <u>Global estimates of incidence and mortality of cervical cancer in 2020: a baseline analysis of the WHO Global Cervical Cancer Elimination Initiative</u>. Lancet Glob Health. 11(2):e197–206. PMID:36528031



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- HPV atlas to support cervical cancer elimination
- IARC Handbook of Cancer Prevention on Cervical Cancer Screening
- IARC Evidence Summary Brief, titled "Protection from a Single Dose of HPV Vaccine: A major public health impact from IARC studies of vaccine efficacy"
- Global estimates of incidence and mortality of cervical cancer in 2020
- WHO Classification of Tumours / Female Genital Tumours
- WHO Cervical Cancer Elimination Initiative

# IARC Global Breast Cancer Initiative (GBCI) Team

#### **Members**

**Team leaders:** Dr Nadya Dimitrova (Public Health Officer), Early Detection, Prevention, and Infections Branch (EPR) and Dr Marion Piñeros (Scientist), Cancer Surveillance Branch (CSU)

**Team members:** The GBCI Team comprises 9 Team members (9 scientists including one postdoctoral scientist) from 3 Branches in IARC Pillars 1 (CSU) and 3 (EPR and ENV).

→ Dr Freddie Bray (Branch Head; CSU); Dr Partha Basu (Branch Head, EPR); Dr Andre Carvalho (Scientist, EPR); Dr Isabel Mosquera (Scientist, EPR); Dr Farida Selmouni (Scientist, EPR); Dr Valerie McCormack (Deputy Branch Head, ENV); Dr Carolina Espina (Scientist, ENV); Dr Milena Foerster (Scientist, ENV); Dr Pauline Boucheron (Postdoctoral Scientist, ENV)



# **Objectives**

#### Context

IARC and WHO have complementary functions and mandates aimed at advancing global cancer control. On 8 March 2021, WHO launched the Global Breast Cancer Initiative (GBCI) with the goal of reducing breast cancer mortality by 2.5% annually. To achieve this objective, three key pillars and specific targets were established:

- Pillar 1: Health promotion for early detection Target: Achieve a diagnosis of at least 60% of invasive cancers at stages I or II.
- Pillar 2: Timely diagnosis

  Target: Complete evaluation, imaging, tissue sampling, and pathology within 60 days.
- Pillar 3: Comprehensive breast cancer management
- Target: Ensure that at least 80% of patients with breast cancer receive a full course of multimodal treatment and successfully return home.

In this context, the objectives of the IARC GBCI Team are:

Facilitating communication: The primary aim of the IARC GBCI Team is to enhance coordination and communication between the WHO and IARC GBCI teams, sharing scientific evidence, expertise, and updates on relevant IARC initiatives and publications.
 Information sharing: The overall objective is to disseminate information and updates on the latest developments concerning ongoing IARC projects, including sharing

insights with WHO and fostering dialogue among IARC groups working on breast cancer initiatives.

The Team's activities, aligned with the GBCI pillars, include:

#### → Development and dissemination of supporting data and tools:

- Estimation of breast cancer burden via the IARC Global Cancer Observatory, which provides information on incidence, mortality, and prevalence for 185 countries or territories.
- Analysis of breast cancer mortality trends by age in 70 middle- and high-income countries (accessible via the Cancer Over Time subsite of the Global Cancer Observatory).
- Reporting of cancer incidence data from high-quality cancer registries worldwide through the periodic publication Cancer Incidence in Five Continents.
- Support for cancer registries in less-developed settings via the Global Initiative for Cancer Registry Development (GICR).
- Collection of breast cancer incidence and survival data by stage and age in about 70 LMICs (SURVCAN-4).
- Estimation of breast cancer prevalence according to phases of care (PrevPhase-1).
- Assessment of the intergenerational impact of premature deaths from breast cancer, specifically concerning maternal orphans.
- Cancer Screening in Five Continents (CanScreen5).



- Development of the World Code Against Cancer Framework and related educational materials for health promoters and frontline health-care professionals.
- Launch of the IARC Learning Portal, including a self-paced learning programme on improving the quality of cancer screening.
- Creation of a digital atlas on clinical breast examination (CBE), diagnostic mammography, breast ultrasound, and breast pathology (Atlas of Breast Cancer Early Detection).
- Development of country-specific breast cancer profiles within the GBCI framework (e.g. Namibia).
- Data collation at IARC to support GBCI pillar key performance indicators (KPIs).

#### Pillar 1: Health promotion for early detection

 Development of standards and recommendations regarding breast cancer incidence by stage at diagnosis at the population level.

#### Governance

Meetings commenced in March 2023 with Dr. Benjamin Anderson from WHO Headquarters. As of January 2024, these meetings have continued with Dr. Mary Nyangasi, Technical Officer for Cancer in the Department of Non-Communicable Diseases, Disability, and Rehabilitation at headquarters/UCN/NCD/MND in Geneva, Switzerland. Dr. Nyangasi serves as the WHO headquarters focal point for the WHO GBCI. A technical working group comprising international partners has been established by WHO, which includes participation from IARC GBCI members.

#### Links with WHO

The GBCI Team maintains a close cooperative relationship with WHO on the WHO GBCI, with Dr. Mary Nyangasi as the primary contact at WHO headquarters.

- Implementation of the World Code Against Cancer Framework and creation of educational materials for health promoters and front-line health-care professionals.
- Establishment of a digital atlas on clinical breast examination (CBE), diagnostic mammography, breast ultrasound, and breast pathology (Atlas of Breast Cancer Early Detection).
- Conducting studies on the patient journey to diagnosis, health system barriers to early detection, and breast cancer awareness levels in LMICs, including sub-Saharan Africa (e.g. ABC-DO study in Namibia, Nigeria, South Africa, Uganda, and Zambia) and Eastern Europe and Asia (e.g. DEDICA multi-country study).
- Evaluation of clinical breast examination (CBE) through a randomized trial.
- Implementation of a multilevel strategy to improve access to early detection and subsequent care for vulnerable rural populations in India (Access Cancer Control India; ACCI).

#### Pillar 2: Timely diagnosis

- Conducting an IARC multicenter study to evaluate novel technologies aimed at improving early breast cancer diagnosis in resource-limited settings in India and Uganda.
- Creation of a digital atlas on clinical breast examination (CBE), diagnostic mammography, breast ultrasound, and breast pathology (Atlas of Breast Cancer Early Detection).

#### Pillar 3: Comprehensive breast cancer management

 Conducting patterns-of-care studies for breast cancer in Morocco, Nepal, Eastern Europe and Asia (e.g. DEDICA multi-country study), and sub-Saharan Africa (e.g. ABC-DO). This includes interventions aimed at improving treatment completion rates.



#### **Key collaborations**

# Cooperation across IARC Branches

The GBCI Team is primarily led by CSU and EPR Branches, which fall under IARC Pillars 1 and 3. The team collaborates with Pillar 1 (CSU) to gather data on breast cancer and engages with Pillar 3 (EPR and ENV) for related efforts. Currently, the Team does not include participants from Pillars 2 and 4.

#### Workplan progress

#### Projects and consortia

- Webpage development: The team is in the process of creating a webpage summarizing relevant IARC projects organized by GBCI pillar, which will include supporting data and tools on the three pillars of the WHO initiative.
- Resource communication: The team is responsible for informing the WHO contact person about available resources, including:
- Data for monitoring breast cancer burden, including stage distribution.
- Training and capacity-building resources related to TNM classification and screening.
- Screening and cancer care organization: Since June 2024, the team has participated in WHO GBCI Technical Working Groups focusing on:
  - o The WHO Global Status Report on Cancer.
  - o Health Systems Strengthening.
  - o Advocacy and Leadership.

#### Applications and grants

No reported applications or grants related to the GBCI Team during the period of 2023-2024.

#### **Main innovations**



- Establishment of an IARC research team formed in alignment with the WHO Global Breast Cancer Initiative.
- Development and dissemination: Focused on creating and distributing supporting data and tools.
- Contribution to WHO Global Initiative pillars through various projects.

# **Contributions to MTS implementation**

IARC's contributions to WHO's Global Initiatives on Cancer are recognized as a priority in the MTS 2021-2025 and are integrated into the IARC-WHO strategic workplan for 2023-2025.

#### Fundamental priorities

The workplan of the GBCI Team directly addresses two fundamental priorities of the MTS 2021-2025:

- → Data for action: Providing estimates of breast cancer incidence, mortality, staging at diagnosis, and projections for 2022–2050.
- → From understanding to prevention: Engaging in projects that contribute to the three pillars of the WHO Global Breast Cancer Initiative.

# **Next steps**

The GBCI Team has outlined the following next steps for the development of the Team:

- → Enhance communication: Strengthen and maintain regular communication with the WHO team responsible for the GBCI.
- → Identify collaboration topics: Explore specific topics for collaboration while investigating the availability of funding.
- → Coordinate efforts: Complement existing efforts on similar projects to avoid duplication of work.



#### RECOMMENDATIONS



As a newly established Team, there is room for improvement in terms of structure and organization:

- ✓ This team addresses a specific need within IARC by facilitating communication between IARC and WHO for the implementation of the WHO GBCI. Meetings between the IARC Team and WHO commenced in January 2024 with the new WHO contact person.
- ✓ The team should actively explore grant opportunities and seek direct funding from WHO headquarters.
- ✓ In the medium term, Team leaders are encouraged to consider consolidating IARC initiatives related to breast cancer, including the team on hormones and breast cancer led by Dr Sabina Rinaldi and Dr Laure Dossus, as well as the Working Group on Breast Cancer. This consolidation could optimize knowledge sharing and resource integration, including the incorporation of Pillar 2 into the team. In addition, integrating participants from Pillar 4 (IARC Handbooks, WHO Classiciation of Tumours) may also be beneficial.

#### **Key publications**

- Znaor A, Eser S, Bendahhou K, Shelpai W, Al Lawati N, ELBasmi A, Alemayehu EM, Tazi MA, Yakut C, Piñeros M. Stage at diagnosis of colorectal cancer in the Middle East and Northern Africa: A population-based cancer registry study. Int J Cancer. 2024 Jul 1;155(1):54-60. Epub 2024 Mar 8. PMID:38456478.
- Benitez Fuentes JD, Morgan E, de Luna Aguilar A, Mafra A, Shah R, Giusti F, Vignat J, Znaor A, Musetti C, Yip CH, Van Eycken L, Jedy-Agba E, Piñeros M, Soerjomataram I. <u>Global Stage</u>
   <u>Distribution of Breast Cancer at Diagnosis: A Systematic Review and Meta-Analysis</u>. JAMA Oncol. 2024 Jan 1;10(1):71-78. PMID: 37943547; PMCID: PMC10636649.
- de Paula Silva N, Colombet M, Moreno F, Erdmann F, Dolya A, Piñeros M, Stiller CA, Steliarova-Foucher E; IICC-3 contributors. <u>Incidence of childhood cancer in Latin America and the Caribbean: coverage, patterns, and time trends.</u> Rev Panam Salud Publica. 2024 Feb 26;48:e11. PMID:38410357; PMCID: PMC10896122.
- Soerjomataram I, Cabasag C, Bardot A, Fidler-Benaoudia MM, Miranda-Filho A, Ferlay J, et al.;
   SURVCAN-3 collaborators (2023). <u>Cancer survival in Africa, central and south America, and Asia</u> (<u>SURVCAN-3</u>): a population-based benchmarking study in 32 countries. Lancet Oncol. 24(1):22–32. PMID:36603919
- Zhang L, Mosquera I, Lucas E, Rol ML, Carvalho AL, Basu P; CanScreen5 collaborators (2023).
   <u>CanScreen5, a global repository for breast, cervical and colorectal cancer screening programmes</u>.
   Nat Med. 29(5):1135–45. PMID:37106168
- Piñeros M, Brierley J, Barrios E, Cueva P, Musetti C, Pardo C, Ward K, Parkin DM. Accuracy of Essential TNM to stage large colorectal (T3/T4) cancers in absence of nodal status information. Acta Oncol. 2023 Dec;62(12):1669–1671. doi:10.1080/0284186X.2023.2257376. Epub 2023 Nov 25. PMID: 37738263.
- Mosquera I, Todd A, Balaj M, Zhang L, Benitez Majano S, Mensah K, et al. (2023). <u>Components and effectiveness of patient navigation programmes to increase participation to breast, cervical and colorectal cancer screening: a systematic review.</u> Cancer Med. cam4.6050. PMID:37245225

#### References

- Web page of the GBCI Team
- Web site of the WHO Global Breast Cancer initiative



# 4.2 Prevention policies

#### Impacts on prevention policies

Main ambitions of the MTS 2021-2025:

 Translation of IARC's scientific production into WHO public health prevention policies

#### KPIs:

- Contribution of the IARC Monographs programme to prevention policies (case study)
- Contribution of the IARC Handbooks to WHO guidelines (case study)
- Codes Against Cancer (case study)
- Documentation on prevention advocacy

Source: ESC, CSU, PLW, ENV, EPR

In addition to the documentation on prevention advocacy, including IARC Evidence Summary Briefs, four types of IARC scientific programmes directly contribute to the definition of public health prevention policies with WHO. Those IARC flagship programmes are: the *IARC Monographs* programme, the *IARC Handbooks* programme, the Codes Against Cancer, and CanScreen5 on secondary prevention.

#### Documentation on prevention advocacy

IARC produces on a regular basis reference documents on prevention advocacy. During the current MTS, it is worth mentioning the following publications for 2021–2024:

- Cancer Incidence in Five Continents Volume XI, IARC Scientific Publication No. 166, 2021
- Cervical Cancer Elimination in Africa: Where Are We Now and Where Do We Need to Be? [joint publication

#### with UICC], 2022

- Best Practices in Cervical Screening Programmes: Audit of Cancers, Legal and Ethical Frameworks, Communication, and Workforce Competencies, IARC Working Group Report No. 11, 2023
- Mise en œuvre d'un programme pilote de dépistage du cancer du col de l'utérus intégré dans les services courants de soins de santé primaires au Bénin, en Côte d'Ivoire et au Sénégal, 2023
- Implementation of a Pilot Cervical Cancer Screening Programme Integrated in Routine Primary Health-Care Services in Benin, Côte d'Ivoire, and Senegal: Repot of a Pilot Project (Care4Afrique) in Three African Countries, 2023
- Atlas of Breast Cancer Early Detection, IARC CancerBase No. 17, 2023
- <u>Using HPV tests for cervical cancer screening and managing HPV-positive women a practical online guide, IARC CancerBase No. 18, 2023</u>
- Uso de pruebas de VPH para el tamizaje del cáncer cervicouterino y el manejo de mujeres VPH positivas: una guía práctica en línea, IARC CancerBase No. 18. 2023
- Atlas de l'inspection visuelle à l'acide acétique du col de l'utérus pour dépister, trier et déterminer l'éligibilité des lésions au traitement ablatif. IARC Cancer Base No. 16, 2023
- Cancer Incidence in Five Continents, Vol. XII, IARC Cancer Base No. 19, 2023
- Atlas de colposcopia principios y prácticat, IARC CancerBase No. 13, 2023
- Атлас кольпоскопии принципы и практика. IARC CancerBase No. 13, 2024
- Assessment of Barriers and Interventions to Improve Cancer Screening Programmes in Latin American and Caribbean Countries: Outcomes of the CanScreen5/CELAC Project, 2024

The IARC Evidence Summary Briefs series also represents some major contributions for prevention advocacy, with one publication per year during the 2021–2024 period:

- The Nutri-Score: A Science-Based Front-of-Pack Nutrition Label. Helping consumers make healthier food choices. IARC Evidence Summary Brief No. 2, 2021.
- Improving Early Detection and Clinical Management of Bladder Cancer. IARC Evidence Summary Brief No. 3, 2022.
- Protection from a Single Dose of HPV Vaccine: A major public health impact from IARC studies of vaccine efficacy. IARC Evidence Summary Brief No. 4, 2023.
- Maternal Orphans due to Cancer: The intergenerational impact of cancer deaths in women. IARC Evidence Summary Brief No. 5, 2024.



# IARC Monographs programme Case study

# **Overview of the project**

#### Objectives and target audience

#### **Summary**

The IARC Monographs programme, established in 1971, is a cornerstone initiative of the International Agency for Research on Cancer (IARC), dedicated to identifying carcinogenic hazards and informing global cancer prevention efforts. The programme rigorously evaluates the carcinogenic hazard of various agents, including chemicals, occupational exposures, physical and biological agents, and lifestyle factors, by synthesizing evidence from human cancer, animal cancer, and mechanistic studies. These evaluations, conducted by expert Working Groups, are published in the IARC Monographs series, which serves as an authoritative resource for researchers, public health authorities, and policymakers.

The primary objective of the *IARC Monographs* programme is to assess the carcinogenic hazards to humans posed by specific agents, encompassing chemicals, complex mixtures, occupational exposures, physical agents, biological agents, and nutritional and lifestyle factors. By providing scientifically robust evaluations of carcinogenic hazards, the *IARC Monographs* support the development of public health policies and regulatory decisions aimed at reducing exposure to potential carcinogens.

The programme also aims to advance methodologies for systematic review in the fields of observational epidemiology, animal bioassay, and mechanistic evidence, ensuring a robust framework for identifying cancer hazards.

The *IARC Monographs* are a critical resource for a diverse audience, including policymakers, regulatory agencies, public health officials, researchers, and industry professionals. These evaluations guide regulatory standards, occupational safety measures, and public health recommendations globally. National health agencies rely on the *IARC Monographs* to shape cancer control policies, particularly in LMICs, where resources for cancer prevention are often limited.

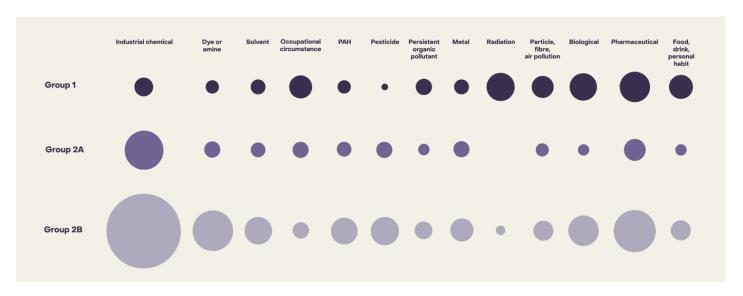
#### History and evolution

The *IARC Monographs* programme began with the first *IARC Monographs* meeting which took place on 13–17 December 1971 in Geneva, Switzerland. The results were published with the distinctive orange cover as Volume 1 of the *IARC Monographs* on the Evaluation of the Carcinogenic Risk of Chemicals to Man in 1972.

Each *IARC Monographs* volume focuses on a specific set of agents and involves a comprehensive review of available and relevant scientific evidence. Over the past five decades, more than 1400 scientists contributed to 134 (published) volumes, and 1045 agents evaluated, with more than 540 classified as carcinogenic (Group 1), probably carcinogenic (Group 2A), or possibly carcinogenic (Group 2B) to humans.



The programme has continually evolved to incorporate advances in scientific methodologies and data sources. The Preamble to the *IARC Monographs* details the methodology used by expert Working Groups to conduct evaluations. It includes principles and procedures for selecting meeting participants, managing conflicts of interest, and applying scientific criteria to classify agents into categories based on the strength of evidence. The 2019 update to the Preamble introduced the use of key characteristics of carcinogens to better integrate mechanistic evidence into evaluations. This allows for a more comprehensive assessment of how agents may cause cancer and reflects the latest scientific understanding. Since then, the key characteristics of carcinogens framework and evidence integrations have been adopted at 14 *IARC Monographs* meetings (Volumes 124–137).



Source: 50 years of the IARC Monographs, 2024.

In 2019, the name of the programme was also updated from *IARC Monographs* on the Evaluation of Carcinogenic Risks to Humans to *IARC Monographs* on the Identification of Carcinogenic Hazards to Humans, clarifying its focus on hazard identification rather than risk assessment. The distinction between hazard identification and risk assessment is fundamental. Whereas hazard identification determines whether an agent can cause cancer under at least some circumstances and levels of exposure, risk assessment estimates the probability of cancer occurring at a given level and type of exposure. The *IARC Monographs* focus on identifying cancer hazards, which are crucial for developing preventive actions even when the risks appear to be low under certain exposure scenarios.

The updated Preamble also reinforces strict management of conflicts of interest and enhanced transparency regarding the role of Working Group members and other meeting participants.

In 2024, an Advisory Group met to recommend <u>IARC Monographs</u> priorities for 2025–2029, assessing more than 200 agents on the basis of human exposure, evidence of cancer in humans and animals, and mechanistic evidence. The Advisory Group emphasized the need to evaluate emerging carcinogenic hazards and suggested a systematic review of all Group 1 agents for potential new cancer sites showing a causal association.

The *IARC Monographs* programme has enhanced its digital presence, offering online access to evaluations and related data. It is also developing a new, publicly available Monographs Database Online (IARC-MonDO), which will expand the accessibility of information from published *IARC Monographs* volumes. Communication tools have also been expanded, including the initiation of a triannual newsletter, with nearly 750 subscribers, advertising calls for experts and data, and



featuring recent evaluations by the *IARC Monographs* programme. These developments facilitate global dissemination and access, particularly for stakeholders in LMICs.

#### Methodology and tools

The programme uses a rigorous, systematic, structured and transparent evaluation process, involving international Working Groups of expert scientists.

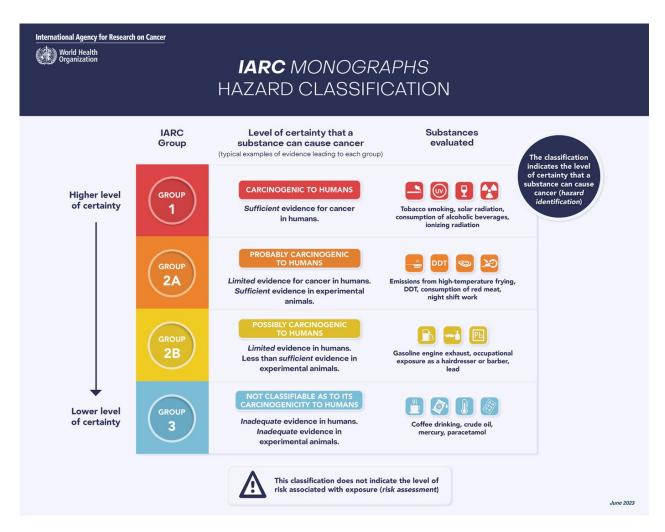
Agents are selected for evaluation based on evidence of human exposure and potential carcinogenicity. The general public, scientific community, national health agencies, and other organizations are invited to nominate agents for review at future meetings. However, priorities for evaluation may also be influenced by the emergence of new scientific information or urgent public health needs.

Selected agents undergo a comprehensive and systematic review by the Working Groups, who meet in subgroups to assess the strength of evidence across three streams: studies of cancer in humans, studies of cancer in experimental animals, and mechanistic evidence. Exposure to humans in different settings is succinctly characterized. Over the 8-day in-person meetings, the subgroups finalize their drafts. The Working Group then meets in plenary session to review the subgroup drafts and develop a consensus evaluation.

The process ensures strict management of conflicts of interest and enhanced transparency. Meetings are announced 1 year in advance, with public calls for data, experts, and observers. All participants (including IARC/WHO Secretariat members) complete a WHO Declaration of Interests form, which is reviewed by senior staff and the IARC Bioethics and Compliance Officer. Participants' names and relevant interests are disclosed 2 months before meetings. Confidentiality agreements protect deliberations, and the presence of representatives and observers from diverse backgrounds, including funding agencies, ensures transparency. The programme limits invited specialists and carefully manages public nominations of experts to avoid conflicts of interest.

For each agent, the evidence is classified into one of four categories based on the strength of the evidence for carcinogenicity: Group 1 (carcinogenic to humans), Group 2A (probably carcinogenic to humans), Group 2B (possibly carcinogenic to humans), and Group 3 (not classifiable as to its carcinogenicity to humans).





IARC Monographs hazard classification.56

The *IARC Monographs* programme convenes two or three meetings annually, during which one or more agents are reviewed. Topics for each meeting are publicly announced approximately one year in advance.

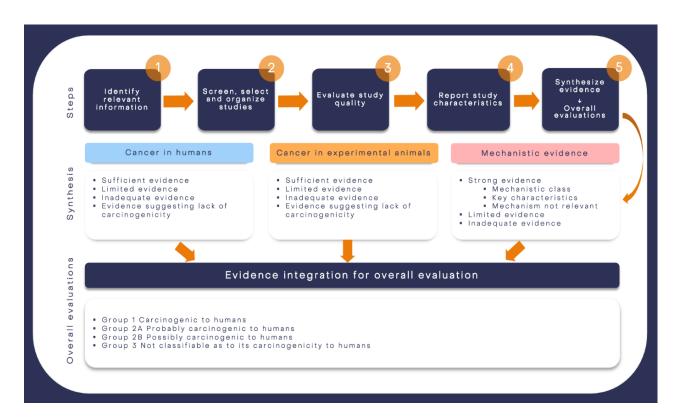
Each *IARC Monographs* volume is developed over a 2-year period, from the announcement of topics on the *IARC Monographs* website to publication of the full text, during which IARC engages with the public in the interest of transparency.

In addition to the evaluation process, the *IARC Monographs* programme organizes scientific workshops on key issues pertaining to the assessment of carcinogens and their mechanisms. Workshop findings are applied by the programme to enhance the rigour and transparency of IARC Monograph evaluations.

The *IARC Monographs* programme has also embraced digital tools to enhance its evaluation process (IOPS, Table Builder, HAWC). A web-developer has been recruited to further develop these tools, as well as the new IARC-MonDO, an enhanced database of the key information from *IARC Monographs* evaluations.

<sup>56</sup> Source: 50 years of the IARC Monographs, 2024.





IARC Monographs evaluation process.57

#### **Structure**

#### Governance framework

The *IARC Monographs* programme is coordinated by the Evidence Synthesis and Classification (ESC) Branch at IARC and operates as part of a specialized programme known as IMO (*IARC Monographs* programme).

It operates under a well-defined governance structure that includes a Secretariat responsible for the overall management and logistical support of the programme.

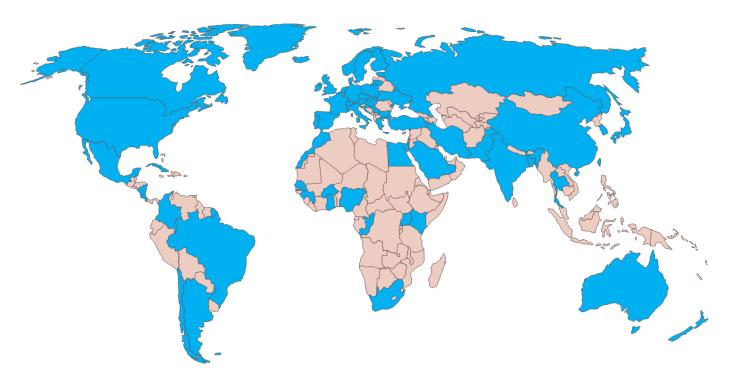
The Secretariat collaborates with expert Working Groups, which are composed of international specialists who review the evidence and draft the *IARC Monographs*. These Working Groups are convened 2–3 times per year (a different Working Group for each volume) and consist of scientists with expertise in epidemiology, toxicology, and other relevant fields.

Since 1971 (*IARC Monographs* Volumes 1–137), more than 1400 scientists from 59 countries have participated in *IARC Monographs* meetings (see the map below). In 2019–2023, 343 scientists (336 Working Group members and 7 Invited Specialists) attended 12 *IARC Monographs* meetings, 1 Advisory Group meeting, and 2 Scientific Workshops. These scientists came from 32 countries across five continents, including LMICs among IARC Participating States, for example from Brazil, the Russian Federation, the Islamic Republic of Iran, China, South Africa, and India.

Members are selected based on their scientific credentials and conflict-of-interest disclosures, with consideration given to gender and geographical balance.

<sup>57</sup> Source: 50 years of the IARC Monographs, 2024.





Map showing the countries of scientists who have contributed to the IARC Monographs programme.<sup>58</sup>

#### International collaborative network

The *IARC Monographs* programme, through its expert Working Groups, serves as a vital network for collaboration between IARC and the global cancer research community.

The programme has also contributed to significant collaborative projects such as the European Code Against Cancer, the French burden of cancer project, and analytical epidemiology studies such as the International Nuclear Workers Study (INWORKS) and Pooled Uranium Miners Analysis (PUMA).

In addition, the programme maintains strong connections with agencies such as the United States National Toxicology Program (NTP) and the European Chemicals Agency (ECHA), ensuring that its evaluations are consistent with global regulatory standards.

#### Resources

The *IARC Monographs* programme is supported by a combination of extramural funding sources, primarily grants from the USA, covering 59% of its budget, and the IARC Regular Budget (RB).

External support comes from institutions such as the United States National Cancer Institute, the United States National Institute of Environmental Health Sciences, and to a lesser extent from the European Commission.

The staff is composed of one Programme Head (RB), 7 Scientists (2 RB and 5 EB), 1 Scientific Editor (RB), 3 Visiting Scientists, 5 Support Staff (3.5 RB and 1.5 EB) and 2 Consultants.

As stated in the ESC Branch Review in 2024, the indicative costs per *IARC Monographs* volume are about €565 448 (€433 736 staff costs and €131 712 non-staff costs).



#### Links with WHO

Over the past 5 years, IMO has strengthened collaborations across WHO, as outlined in the interim SOP. These efforts align with IARC's contributions to the global United Nations Non-Communicable Disease (NCD) strategy, focusing on cancer prevention and the identification of cancer risk factors with a global impact.

The *IARC Monographs* programme has occasionally faced some resistance about evaluating cancer hazards followed by WHO's risk assessments, particularly with food additives and pesticides. In 2023, IARC coordinated with the Joint FAO/WHO Expert Committee on Food Additives (JECFA) programme to coordinate a cancer hazard evaluation (IARC) and risk assessment (JECFA) for aspartame, a commonly used artificial sweetener. IARC has not conducted a *Monographs* evaluation of a pesticide in nearly a decade due to these difficulties. Ongoing discussions with the FAO/WHO Joint Meeting on Pesticide Residues (JMPR) have successfully addressed these issues, and Meeting 140 of the *IARC Monographs* will evaluate three pesticides.

IMO regularly invites experts from WHO headquarters and regional offices to participate in its *IARC Monographs* advisory meetings, and a manager of the WHO JECFA/JMPR programmes participated in the 2024 Advisory Group to Recommend Priorities for the IARC Monographs during 2024–2029.

Opportunities exist to further coordinate hazard identification by IMO and risk assessment in WHO food safety programmes, as successfully demonstrated with the aspartame monograph in Volume 134. In addition, IMO has contributed to the Global Occupational Burden of Disease Project led by WHO, in particular related to solar ultraviolet radiation and skin cancer.

# Global reach and impact

#### Bridging HICs innovation with LMICs access

As demonstrated with many of the agents recently evaluated in the *IARC Monographs*, there is significant and ongoing global human exposure (e.g. occupational exposure as a firefighter, aspartame, PFOA and PFOS, talc), often with particular relevance to LMICs (e.g. night shift work, opium consumption, arecoline).

Concerns were raised about whether the *IARC Monographs* programme adequately addresses issues relevant to LMICs, where exposures to hazardous agents can be more intense and impactful. Despite efforts, data on exposure levels and epidemiological information specific to LMICs are often limited, but the *IARC Monographs* programme has taken steps to identify databases specific to under-represented regions of the world (e.g. China).

The *IARC Monographs* have taken steps to prioritize evaluating agents of concern to LMICs, such as opium and arecoline in betel quid, which are linked to high oral cancer rates in the Islamic Republic of Iran, India, and parts of East Asia.

To increase accessibility, the *IARC Monographs* programme is enhancing digital platforms through the implementation of the IARC-MonDO, which will provide easy access to *IARC Monographs* content (see "I. Summary, 4. Methodology and tools).

Efforts also include integrating early-career and visiting scientists from LMICs into *IARC Monographs* meetings and research activities. This includes attracting postdoctoral fellows and visiting scientists from LMICs, providing training in systematic review and evidence synthesis, and hosting IARC-wide visiting scientists focused on high-priority topics. *IARC Monographs* scientists also contribute to training courses, benefiting students from LMICs and promoting the



methods of systematic review within these regions. The recent publication in the Statistical Methods in Cancer Research series, titled Bias Assessment in Case—Control and Cohort Studies for Hazard Identification, describes practical methods for the appraisal of the direction and magnitude of biases in evidence synthesis. Filled with real-life worked examples, this volume should provide essential training to the research community, including those in LMICs.

#### Impact on global cancer prevention policies

Although IMO does not issue public health policy recommendations, the *IARC Monographs* provide independent and critical data that inform cancer prevention policies and research priorities. Recognized as the global standard for carcinogen classification, these evaluations have influenced regulations and guidelines in more than 100 countries, affecting industries, environmental standards, and public health initiatives. Over the past 5 years, the *IARC Monographs* have been cited more than 40 times in US regulations and nearly 100 times in EU legislation.

The *IARC Monographs* were influential in the setting of policies on tobacco control and played a key role in decisions to ban sunbeds in numerous countries.

The classification of opium consumption as a carcinogen (Group 1) has led to significant policy actions in the Islamic Republic of Iran. A Memorandum of Understanding (MoU) was signed between the Drug Control Headquarters of the Islamic Republic of Iran and the Medical Council to develop and implement policies aimed at reducing opium addiction. This includes enhancing medical professionals' knowledge of addiction and treatment and creating prevention and rehabilitation programmes. In November 2020, the Ministry of Health prohibited prescribing street opium for pain relief, with legal consequences for violations. Awareness campaigns, seminars, and media outreach have been widely used to disseminate information on the harms of opium consumption.

The evaluation of occupational exposure as a firefighter as a carcinogen (Group 1) in June 2022 has also had significant impact. According to Scopus, the meeting summary in The Lancet Oncology has been cited 98 times, ranking in the 93<sup>rd</sup> percentile of similarly aged articles. The evaluation has received extensive media coverage and generated nine policy citations to date. Fire units globally are implementing measures to raise awareness and reduce carcinogenic exposures.

Information from *IARC Monographs* evaluations has increasingly been used to support global and country-specific estimates of the burden of disease. Examples of these contributions include:

- The European Code Against Cancer (ECAC);
- Joint WHO/International Labour Organization (ILO) project of work-related burden of disease and injury, related to estimating the burden of occupational cancer from exposures to welding fume exposures and ultraviolet radiation;
- Contributions to the International Commission on Radiation Protection and Measurement (ICRP):
- New estimates of cancer risk for radiogenic cancers, by the United Nations Scientific Committee on the Effects of Atomic Radiation (UNSCEAR).

In addition, the *IARC Monographs* programme can leverage its network to amplify public health impact. For example, the coordinated effort between IMO and the Joint FAO/WHO Expert Committee on Food Additives (JECFA) to release findings on aspartame simultaneously facilitated the understanding of the public health implications of the two reviews.

IMO scientists, especially the Programme Head, are often sought to serve on expert committees or contribute to policy forums, for example, a keynote lecture in the European Educational Programme in Epidemiology in 2023, the French Ministry of Health round table on radiation-



induced cancer in 2021, the NCI's virtual Workshop on Breast Cancer and the Environment, WHO Chemical Risk Assessment Network, French Agency for Food, Environmental and Occupational Health and Safety (ANSES) among others. IMO also contributed to the Chemical and Toxins Taskforce within the WHO foodborne disease burden epidemiology reference group and served as a Secretariat member of the Joint FAO/WHO Expert Committee on Food Additives (JECFA).

IMO scientists also represent IARC in key occupational cancer research agendas (e.g. US National Occupational Research Agenda, 2019—present) and European occupational cohort networks (e.g. OMEGA-NET European Occupational Cohort Consortium 2022; Epidemiology in Occupational Health, EPICOH).

# **Interface with other Pillars and Branches**

The availability of expertise at IARC in the different areas of research used in *IARC Monographs* evaluations facilitates strategic activity involving other Branches in collaborative work with the *IARC Monographs* scientists. Collaborations include the identification of major research gaps and research recommendations in high-priority agents classified in Groups 2 and 3, a follow-up of advances made across the prioritized agents in the 13 years since the recommendations, optimal approaches for hazard and risk communication, and the 2024 IARC Scientific Publication on bias assessment in case—control and cohort studies used for cancer hazard identification.

Pillai 1	Pillar 2	Pillar 3	Pillar 4
	NME: Participates in the Bias Impact and Key Characteristics Scientific Workshops (led by IMO). IMO participates in research projects on chemoinformatic approaches	EGM: Participates in the Key Characteristics Scientific Workshop (led by IMO). IMO participates in research projects on epigenetic mechanisms and on mutation spectra induced by carcinogenic agents (led by EGM)  ENV: IMO participates in the European Code Against Cancer (led by ENV) and on analytical epidemiology research projects (e.g. INWORKS).	Strong connections in ESC between IMO, IHB, and WCT, with increasing coordination across their activities. This includes aligning systematic review methodologies and integrating etiological and preventive findings among the IARC Monographs, the IARC Handbooks, and WCT volumes where relevant.  LCB: IMO participates in the IARC Summer School and created video learning tools about cancer hazard
			identification.

*IARC Monographs* Advisory Group: Scientists from all IARC Branches participate in the Advisory Group meetings; 42 scientists (ranging from master's students and postdoctoral fellows to IARC Branch Heads and including experts from WHO headquarters and regional offices) have participated in *IARC Monographs* Advisory Group meetings at least once as members in the past 5 years. Notably, this is a 30% increase over the previous period.

IARC publications: IMO scientists contributed to the IARC's World Cancer Report (as associate editor, chapter co-author, and peer reviewers). IMO scientists led the development of the IARC Scientific Publication Statistical Methods in Cancer Research, Vol. V on bias assessment in case-control and cohort studies.



Collaborative grants: IMO scientists have contributed to grant applications by other Branches, particularly in relation to carcinogen mechanisms.

Cross-cutting Working Groups and Committees: IMO scientists are part of the Occupational Epidemiology cross-cutting IARC team led by ENV, the Childhood Cancer Research team led by CSU, the IARC Committee for a Sustainable Research Agency, the IARC Postdoctoral Charter Review Committee, the Committee for Relaunch of the Science Café, the Early Career Scientist mentoring committee, the Occupational Health and Safety Committee, the Science Forum Committee, the Reward and Recognition Committee, and the 2022–2023 IARC Fellowship Selection Committee.

Advocacy: Ongoing work with the Knowledge Manager and associated staff in the Communications programme on development of systematic review methods, particularly regarding literature searches and methods to effectively communicate about cancer hazard identification with a variety of audiences.

# **Key Performance Indicators (KPIs)**

The IARC Monographs programme is evaluated through several KPIs:

- → Publication metrics: The programme focuses on the number of *IARC Monographs* volumes published annually, the time from meeting to publication, and the citation impact.
- → Communication and outreach: The programme emphasizes its outreach through the number of training workshops and seminars, and its engagement across media and online platforms, including the number of *IARC Monographs* newsletters published annually.
- → Systematic review and tools: The development and frequent updates of systematic review methods (e.g. the new volume on bias assessment in the Statistical Methods in Cancer Research Scientific Publication series), tools such as HAWC and the IARC-MonDO, and adherence to systematic review protocols are monitored.
- → Innovations: IMO places significant emphasis on innovations in cancer hazard evaluation, using this as a key qualitative metric.

The 2019-2023 KPIs highlights concluded that the *IARC Monographs* programme produced timely, authoritative, and impactful publications with high relevance to LMICs and enhanced communication and outreach. Innovations include the implementation of a rigorous revised Preamble, advancements in systematic review methods and tools, a landmark IARC Scientific Publication on bias assessment in observational epidemiology studies in the context of cancer hazard identification, and the advancement of the key characteristics framework for evaluating mechanistic data.

# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

Involvement in the creation and development of collaborative networks: IARC seeks "to promote international collaboration in cancer research".

→ The *IARC Monographs* programme serves as a key facilitator of international collaboration between IARC and the global cancer research community, leveraging its extensive network of experts and involvement in joint research initiatives (see II. "Structure").



Knowledge mobilization and capacity-building: "IARC will ensure that relevant cooperation activities are conducted in a balanced manner across all continents and regions."

- → IMO is committed to enhancing global research capacity through active participation in training and educational programmes. Senior scientists, particularly the Programme Head, engage in teaching and mentorship activities, contributing to initiatives such as the IARC Summer School's Occupational and Environmental Cancer Epidemiology unit (2019, 2021, 2023). They have also given lectures at Yale University, in Lyon for University of Chicago students, and at the European Educational Program in Epidemiology in Florence, Italy.
- → During the past 5 years IMO scientists have been invited to present keynote lectures on five continents, including in LMICs among IARC Participating States (e.g. Brazil and China), covering diverse topics related to cancer hazard identification. The organizers were WHO headquarters and regional offices, national and international scientific conferences, European and national parliamentary committees,

agencies, and institutions. → In addition, IMO regularly hosts students, postdoctoral fellows, and visiting scientists, particularly from LMICs (including Brazil and the Islamic Republic of Iran), to work on projects

related to systematic reviews and carcinogenic hazard evaluations.

#### Integration into the IARC Project Tree

The IARC Monographs programme is integrated into the IARC Project Tree, contributing to several key objectives:

**Level 2 objective**: The *IARC Monographs* programme supports Level 2 Objective #4, "Synthesizing and mobilizing knowledge and strengthening global capacities in cancer science."

#### Level 3 objectives:

- → Objective 4.3: "Strengthen global knowledge and capacities to implement effective, quality-assured interventions."
- → Objective 4.4: "Enhance understanding of the causes of human cancer through cancer hazard evaluations of the available evidence base by leading independent experts."

Independent and transparent research: "IARC will strengthen its capacity to work in a politicized health environment while maintaining its neutral and independent position, including by forging strategic relationships with similarly independent and internationally operating partners".

→ The IARC Monographs programme has strengthened its transparency processes (see I. Overview of the programme, 3. Methodology and tools), reinforcing IARC's comparative advantage #4: "Independent and impartial authority on carcinogenicity and cancer burden". The programme prioritizes the openness of its review processes and is committed to developing new tools to further increase the transparency and accessibility of its evaluations.

#### Achievements of assigned objectives

Production of evaluations: "IARC will continue to provide definitive unbiased assessments of carcinogenic hazards in the form of the IARC Monographs on the Identification of Carcinogenic Hazards to Humans. IARC Monographs evaluations will be conducted according to principles and procedures outlined in a recently modernized Preamble, which incorporates scientific innovations and increased rigour of systematic review methods. The results will be disseminated rapidly as published scientific summaries, followed by the timely publication of the full Monographs.

- → In 2021-2024, the IARC Monographs programme has been actively evaluating a range of agents for their potential carcinogenic hazards. Key activities during this period include:
  - 2021 activities: Two remote Working Group meetings (Volumes 129 and 130) evaluated 10 agents, including chemicals such as 1,1,1-Trichloroethane and Gentian Violet. Three volumes were published: Volume 126 on opium consumption, Volume 127 on aromatic amines, and Volume 128 on chemicals such as acrolein and arecoline.
  - 2022 activities: Meetings 131 and 132 focused on occupational exposures, assessing agents such as cobalt compounds and firefighters' occupational exposure. Two



- volumes were published (129 and 130), and a scientific workshop on bias assessment in cancer hazard identification was held.
- 2023 activities: Three meetings (133–135) assessed agents such as perfluorooctanoic acid and aspartame, which received significant attention. Two volumes were published: Volume 131 on cobalt and antimony compounds and Volume 132 on firefighter exposure. Workshops focused on evaluation of mechanistic evidence.
- 2024 activities: The Advisory Group convened to set priorities for 2025–2029.
   Meetings 136 and 137 evaluated talc, acrylonitrile, and certain pharmaceuticals. Volumes 133 and 134 and the IARC Scientific Publication on bias assessment in epidemiological studies were published.

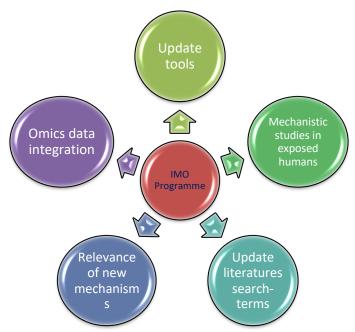
# Main challenges and future perspectives

#### Challenges

- The small team in IMO handles complex and diverse evaluations, necessitating reliance on external resources. Limited funding restricts the capacity to evaluate all suitable agents. Some *IARC Monographs* topics, such as pesticides and food additives, are seen as controversial, complicating collaboration and communication with stakeholders. The programme's dependence on a single major funder in the USA for 59% of its support poses a significant risk if funding priorities shift, a risk heightened through lobbying from stakeholders and political pressure on major funding agencies. In addition, there is reputational risk to the Agency if conflicts of interest are inappropriately handled or if the high quality of *IARC Monographs* evaluations is not maintained. It is crucial to secure diverse funding sources to ensure independence and maintain high evaluation standards, which have kept the programme running smoothly to date.
- The programme cannot allocate resources to fill research gaps identified in evaluations.
  Although IMO scientists have been instrumental in initiating, facilitating, and contributing to
  research collaborations across major international institutions, translating IARC Monographs
  findings into public health action requires additional institutional support. Increased
  collaboration with international and national bodies could enhance the impact of the
  evaluations.
- The *IARC Monographs* programme may face difficulties in recruiting Working Group experts for specific topics due to the complexity or perceived controversy.
- The programme's activities need to be better integrated with LMICs priorities, in alignment with IARC's strategy. Strengthening networks and articulating the relevance of IMO activities to the wider WHO community and LMICs is essential.
- As demand for clear communication of hazard identification increases, there is a need for improved capacity to address these demands. Enhancing communication resources within the programme or leveraging external support is necessary to meet these challenges.



#### **Perspectives**



IARC Monographs programme future directions. 59

- → The IARC Monographs programme will continue evaluating carcinogenic hazards with independent experts, focusing on agents of importance to public health worldwide. Volume 137 (November 2024) evaluated hydrochlorothiazide, voriconazole, and tacrolimus, focusing on drugs with photosensitizing properties. All three drugs were classified in Group 1 (carcinogenic to humans). Upcoming meetings will address automotive gasoline additives and viruses such as hepatitis D virus and human cytomegalovirus. A meeting on three pesticides (atrazine, alachlor, and vinclozolin) was announced for October 2025.
- → The programme is committed to leading advancements in the evaluation of approaches to synthesize cancer epidemiology evidence and toxicological mechanistic evidence in hazard identification. It will build on key outcomes from recent IARC workshops to enhance the use of bias assessment tools, as well as mechanistic evidence, incorporating bioinformatics, high-throughput screening data, and omics integration to identify and evaluate new agents.
- → IMO plans to host a third scientific workshop to address major scientific developments in animal carcinogenicity evidence. This workshop will inform future *IARC Monographs* and foster collaboration with international research institutions.
- → The programme will continue to prioritize transparency by refining systematic review tools and approaches, incorporating detailed evidence syntheses.
- → The IARC-MonDO database will be populated and deployed, which will document the information contained within the *IARC Monographs*. This will support global cancer prevention efforts by enabling detailed analysis across agents, cancer types, and exposure settings. The database will be integrated with the Global Cancer Observatory to facilitate detailed data analysis on cancer causes and exposure settings.
- → A 5-year project is planned to re-evaluate all Group 1 agents for additional cancer sites. Securing sustainable funding from sources such as the EU would support this initiative.
- An important long-term goal is to identify and pursue more stable sources of funding for the IMO programme to sustainably carry out its work.

#### For more details

- → IARC Monographs website
- > 50 years of the IARC Monographs
- Advisory Group recommendations on priorities for the IARC Monographs during 2025-2029.



# IARC Handbooks programme Case study

#### **Summary**

The IARC Handbooks of Cancer Prevention programme produces a series of evaluations of interventions and strategies that can reduce the risk of cancer or of mortality from cancer. The principles of systematic review are applied to the identification, screening, synthesis, and evaluation of the evidence.

The IARC Handbooks are used worldwide by public health representatives to set guidelines and recommendations for cancer prevention.

# **Overview of the project**

#### Objectives and target audience

The *IARC Handbooks* series provides comprehensive reviews and consensus evaluations of cancer prevention interventions and strategies for primary or secondary prevention. The main objective is to assess the effectiveness of potential preventive measures, from lifestyle changes to community-wide interventions, in reducing cancer incidence or mortality from cancer.

The *IARC Handbooks* series targets a broad audience, including governments, health-care professionals, and researchers. Public health authorities use the scientific evidence provided to shape national cancer control policies and programmes. Clinicians and public health experts rely on the IARC Handbooks for guidance on implementing screening initiatives and vaccination campaigns, and turning lifestyle recommendations into clinical practice. Researchers use these evaluations to explore new research avenues and validate interventions. In addition, NGOs and advocacy groups use the evidence to promote cancer prevention strategies and advocate for policy changes.

#### History and evolution

The *IARC Handbooks of Cancer Prevention* series was established in 1995, extending the mission of the *IARC Monographs* by focusing on cancer prevention. After a 5-year hiatus, the series was relaunched in 2014, with a small Secretariat within the *IARC Monographs* programme. In 2017 it became its own programme.

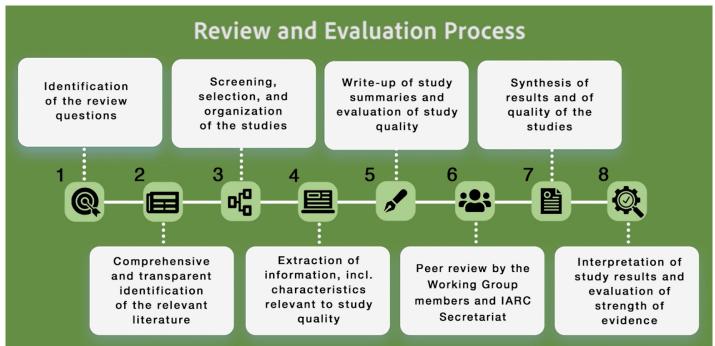
The first *IARC Handbooks* volumes focused mainly on primary prevention measures (e.g. chemopreventive agents, dietary agents, physical activity). The scope of the programme then expanded to cover secondary prevention (screening for cancers of the breast, colon, cervix, oral cavity) and policy interventions (tobacco control, alcohol control). As the scientific landscape progresses, the *IARC Handbooks* include evaluations of new preventive interventions, reflecting the latest developments in cancer control strategies.

Since its relaunch in 2014, the programme has published one *IARC Handbooks* volume every 18 months.



#### Methodology and tools

IARC's process for developing *IARC Handbooks* engages international, expert scientific Working Groups in a transparent synthesis of the available evidence, which is then translated into an overall evaluation according to criteria defined by the Programme. For each new volume of the *IARC Handbooks*, IARC selects a topic for review by considering the availability of pertinent research studies, the need to evaluate an important development in cancer prevention, or the need to reevaluate a previously evaluated intervention. IARC also considers public health priorities in specific geographical regions.



The IARC Handbooks review and evaluation process<sup>60</sup>

Based on the topic under consideration, the systematic review performed for the *IARC Handbooks* may include epidemiological studies only, or both epidemiological and experimental studies (studies in experimental animals and mechanistic studies). Consensus evaluations of the strength of the evidence of cancer-preventive effects of the intervention are made using transparent criteria. Benefits and harms are two fundamental concepts underlying the evaluation of preventive interventions. Other issues that may be considered in implementation of a preventive intervention include the cost, cost-effectiveness, affordability, economic efficiency, health equity impact, feasibility, acceptability, relative value, and human rights impact of the intervention.



The time frame and milestones for the development of a volume of the *IARC Handbooks* are summarized in the table below.

Approximate time frame	Milestones		
~1 year before a <i>Handbooks</i> meeting	IARC posts on the <i>Handbooks</i> programme website:		
	Preliminary List of Interventions to be reviewed		
	Call for Data and Call for Experts open Requests for Observer Status open		
	WHO Declarations of Interests form		
~8 months before a <i>Handbooks</i> meeting	Call for Experts closes		
~4 months before a <i>Handbooks</i> meeting	Requests for Observer Status close		
~2 months before a <i>Handbooks</i> meeting	IARC publishes the names, principal affiliations, and declared conflicts of interest of all meeting participants, and a statement discouraging contact of Working Group members by outside parties		
~1 month before a <i>Handbooks</i> meeting	Call for Data closes		
Handbooks meeting			
~2–4 months after a <i>Handbooks</i> meeting	IARC publishes a summary of evaluations and key supporting evidence as a scientific article in a high-impact journal or on the <i>Handbooks</i> programme website		
~9–12 months after a <i>Handbooks</i> meeting	IARC Secretariat publishes the verified and edited master copy of the plenary drafts as a <i>Handbooks</i> volume		

Time frame and milestones for IARC Handbooks<sup>61</sup>

#### **Structure**

#### Governance framework

The governance of the *IARC Handbooks of Cancer Prevention* is defined in the Preambles and in the Standard Operating Procedure (SOP) established by IARC and WHO in 2024.

Five categories of participants are present at the *IARC Handbooks* meetings: Working Group members, Invited Specialists, Representatives of national and international health agencies, Observers, and IARC/WHO Secretariat. WHO personnel are invited to participate in the *IARC Handbooks* meetings as members of the IARC/WHO Secretariat. Working Group members and Invited Specialists serve as individual scientists and not as representatives of any organization, government, or industry.

#### International collaborative network

After *Handbooks* Volume 19, the Programme established the Oral Cancer Team as a new IARC Research Team, dedicated to advancing research on oral cancer prevention and control. The Oral Cancer Team includes external members from representative countries as well international collaborative networks (e.g. Headspace).

The *Handbooks* is involved in a WCRF-led project, alongside the Nutrition and Metabolism Branch, CUP Global, and several expert Working Groups, assessing the mechanistic links between diet, nutrition, physical activity, and cancer.

The *Handbooks* provides key scientific and programmatic expertise in the EUCervScreen-QA project, for the development of European recommendations for cervical cancer screening and quality assurance guidelines for the cervical cancer screening.

<sup>61</sup> Source: Preamble to the IARC Handbooks of Cancer Prevention for Primary Prevention.



Category of participant	Role			
	Prepare text, tables, and analyses	Participate in discussions	Participate in evaluations	Eligible to serve as Meeting Chair or Subgroup Chair
Working Group members	V	<b>√</b>	<b>√</b>	√
Invited Specialists	$\sqrt{a}$	$\checkmark$		
Representatives of health agencies		√b		
Observers		√b		
IARC Secretariat	√c	√	$\sqrt{d}$	

<sup>&</sup>lt;sup>a</sup> Only for sections not directly relevant to the evaluation

Roles of participants at IARC Handbooks meetings.62

#### Resources

The program of the *IARC Handbooks of Cancer Prevention* programme relies mainly on one P3 scientist staff on Regular Budget (RB), two P2 scientists staff on EB, two Visiting Scientists/Senior Visiting Scientists, a secretary/documentalist on EB, as well as a publication team and web developer shared with the *IARC Monographs* programme. The Temporary Advisors contributing to the IARC Handbooks do not receive any remuneration. The programme funding is secured mostly until 2027 through the IARC Handbooks-specific grants as well as long-term non-competitive grants.

The main historical funders of the programme are: the Foundation for Promotion of Cancer Research in Japan, German Federal Ministry of Health, French Ministry of Health, French National Cancer Institute (INCa), Bill & Melinda Gates Foundation through the Alliance for Cervical Cancer Prevention (ACCP), World Cancer Research Fund (WCRF), American Cancer Society (ACS), Centers for Disease Control and Prevention, USA (CDC), Medical Research Council, United Kingdom (MRC), and Canadian Partnership Against Cancer.

Currently the main funders of the programme are CDC and ACS in the USA, INCa in France, the WHO Regional Office for Europe, and UICC. With the exception of the funders in the USA, the *IARC Handbooks* funders tend to support the programme on a project basis. External funding of the programme represented €250 000 for Volume 18, €370 000 for Volume 19, €420 000 for Volume 20A, €300 000 for Volume 20B, and €300 000 for Volume 21.

As stated in the ESC Branch Review in 2024, the indicative costs per *IARC Handbooks* volume are about €749 468 (€557 493 staff costs and €191 975 non-staff costs).

<sup>&</sup>lt;sup>b</sup> Only at times designated by the Meeting Chair and/or Subgroup Chair

<sup>&</sup>lt;sup>c</sup> Only when needed or requested by the Meeting Chair and/or Subgroup Chair

<sup>&</sup>lt;sup>d</sup> Only for supporting Working Group members and for clarifying or interpreting the Preamble

 $<sup>\</sup>ensuremath{\mathsf{62}}$  Source: Preamble to the IARC Handbooks of Cancer Prevention for primary prevention



#### **Links with WHO**

The IARC Handbooks of Cancer Prevention Programme programme is a relevant example of collaboration with WHO. The topics reviewed are close to the WHO NCDs agenda, and the evaluations can be used directly by WHO to develop recommendations (see III. Global reach and impact). All recent volumes of the IARC Handbooks have integrated some collaboration with WHO to a certain extend: Volume 18 on Cervical Cancer Screening with WHO headquarters, Volume 19 on Oral Cancer Prevention with the WHO Regional Office for South-East Asia, and Volume 20 on Alcohol Control with the WHO Regional Office for Europe.

Volume 18 on Cervical Cancer Screening coincided with the WHO call for the Cervical Cancer Elimination Initiative. The evaluations were used as the basis to update the WHO Guideline for Screening and Treatment of Cervical Pre-Cancer Lesions for Cervical Cancer Prevention. The IARC Handbook and the WHO guideline were developed jointly and in parallel and were launched at a joint webinar attended by more than 500 participants worldwide.

Volume 19 on Oral Cancer Prevention was conceived with a strong focus on South-East Asia and was developed in consultation with the WHO Regional Office for South-East Asia. The supplement on the cost-effectiveness analyses of oral cancer screening and of behavioural interventions to quit smokeless tobacco is currently being developed with WHO headquarters.

Volume 20 on Alcohol Control was a request from and developed in close collaboration with WHO. Part B of the volume, on alcohol control policies, is partly funded by the WHO Regional Office for Europe and developed in collaboration with both WHO headquarters and the WHO regional office.

# **Global reach and impact**

#### Bridging HICs innovation with LMICs access

Some recent volumes of the IARC Handbooks were specifically targeting LMICs, such as Volume 18 on Cervical Cancer Screening and Volume 19 on Oral Cancer Prevention.

The representation of LMICs among Working Group members has increased substantially during the past 5 years, from 21% to 35%; 7 countries were newly represented, mostly LMICs.

In addition, the *IARC Handbooks programme* contributes to increasing training capacity in LMICs by selecting ECVSs from those countries.

#### Impact on global cancer prevention policies

The evaluations of the *IARC Handbooks* are used by national and international health agencies to develop evidence-based interventions or recommendations for reducing cancer risk. As an example, the evidence provided by the *IARC Handbooks* on tobacco control informed the creation of the WHO Framework Convention on Tobacco Control (FCTC), now adopted by more than 180 countries.

In a similar vein, the *IARC Handbooks'* evaluations of breast, cervical, and colorectal cancer screening programmes have led to the adoption of evidence-based screening guidelines. Handbooks Volume 18 was used as a basis to update the WHO Guideline for Screening and Treatment of Cervical Pre-Cancer Lesions for Cervical Cancer Prevention.



Volume 19 on Oral Cancer Prevention had a special focus on South-East Asian countries, where oral cancer is a leading cause of death. The outcomes were particularly impactful in this region. For instance, scientists were invited to a Technical Workshop for WHO South-East Asia Region Member States held in Bangkok, Thailand, to present the results and discuss how countries can improve oral cancer control.

The *IARC Handbooks* programme is working with WHO on cost-effectiveness analyses of oral cancer screening and behavioural interventions to quit use of products that contain smokeless tobacco and/or areca nut. The results of that analysis will be critically important for the development of oral cancer screening recommendations and guidelines, and for helping governments to make decisions on implementing oral cancer screening.

IARC was a member of the International Working Group that developed a framework for the evaluation of new non-invasive colorectal cancer screening tests.

#### **Interface with other Pillars and Branches**

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU: Collaborations on cancer incidence data and population attribuable fractions (PAF)	NME: Collaborations on nutrition and obesity  GEM: Collaboration on oral cancer	EPR: Collaborations on oral cancer screening, and on cervical cancer screening	Strong connections within ESC, with increasing coordination across their activities. This includes aligning systematic review methodologies and integrating findings among IARC Monographs, IARC Handbooks, and WCT volumes where relevant.  Collaborations with the IARC Monographs on key characteristics for obesity  LCB: Collaborations on the IARC Summer School, and on e-learning modules

# **Key Performance Indicators (KPIs)**

The *IARC Handbooks of Cancer Prevention* programme relies on some **quantitative indicators** corresponding to:

- → The number of consultations of the *IARC Handbooks* publications in the New England Journal of Medicine.
- → The number of downloads of the IARC Handbooks on the IARC Publication website,
- → The press coverage of the publications,
- → The coverage of the *IARC Handbooks* in social media networks, etc.



The programme also relies on some **qualitative indicators** showing the impacts of its publications on public health policies. The following contributions were identified for the three *IARC Handbooks* published during the MTS 2021–2025 period:

- → IARC Handbooks Volume 18 on Cervical Cancer Screening established the evidence regarding the performance of HPV-based cervical cancer screening that served as basis for the updated WHO guidelines and also led to the recommendation against Romanowsky-Giemsa staining. Volume 18 and the updated WHO guidelines are pivotal in the realization of the second objective of the WHO Cervical Cancer Elimination Initiative by reaching, globally, at least 70% of women eligible for cervical cancer screening.
- → IARC Handbooks Volume 19 on Oral Cancer Prevention has been used in the WHO Global Oral Health Report and for a workshop at the WHO Regional Office for South-East Asia to help implementation of oral cancer control. A major impact has been achieved on oral health services in Papua New Guinea.
- → IARC Handbooks Volume 20A on Reduction or Cessation of Alcoholic Beverage Consumption has contributed to the statement by the European Commission and to the Global WHO Forum at WHO headquarters for implementation of alcohol control globally.

# **Alignment with IARC MTS 2021-2025**

#### Contribution to IARC's mission

Involvement in the creation and development of collaborative networks: IARC seeks "to promote international collaboration in cancer research".

- → The programme serves as a hub for global collaboration among cancer researchers through its meetings and initiatives. In 2019-2023, 67 scientists from 26 countries, representing all six WHO regions, participated in IARC Handbooks meetings.
- → In addition to the *IARC Handbooks* meetings, the programme has been the leader or a major contributor for the creation and development of collaborative networks with internal and/or external scientists (see "II. Structure, 3. International collaborative networks).

# Integration into the IARC Project Tree

The IARC Handbooks of Cancer Prevention programme is part of Level 2 objective of IARC Project Tree #4 "Synthesizing and mobilizing knowledge and strengthening global capacities in cancer science".

It contributes to the **Level 3 objectives**:

→ Objective 4.3: "Strengthen global knowledge and global and national capacities to implement effective, quality-assured, affordable interventions".

Knowledge mobilization and capacity-building: "IARC is well placed to develop appropriate and tailored capacity-building programmes and to identify the most relevant target audiences for training or mentoring activities."

- → The programme created educational materials, chaired webinars, and developed e-learning tools based on the World Cancer Report series.
- → IARC Summer School: the programme chaired debates and sessions focusing on cancer risk reduction in LMICs, and hosted "Meet the Scientists" sessions in 2021 and 2023.
- → IARC scientists presented at numerous internal and external events, such as the IARC/WHO Regional Office for Europe workshop on cancer screening and the Science Café Seminar Series, focusing on topics such as cancer screening methods and public health interventions. They also contributed to joint IARC and CLB seminars, promoting scientific dialogue and community engagement. In addition, workshops such as the "Cancer in Africa" science forum and sessions on colorectal cancer etiology highlighted collaborative research efforts.
- → Junior Scientists were actively involved in the *IARC Handbooks* preparation, providing valuable learning opportunities for more than 15 early-career scientists through participation in meetings and collaborative projects.



#### Achievements of assigned objectives

Production of evaluations: "IARC will continue to assess the effectiveness of selected preventive interventions through comprehensive, systematic reviews and consensus evaluations of the relevant evidence. Results in the form of the *IARC Handbooks of Cancer Prevention* support national and international health authorities in developing relevant evidence-based interventions or policy recommendations". During the MTS period, "IARC will evaluate and publish a IARC Handbook on oral cancer prevention, with a particular focus on populations in South Asia, where oral cancer is a major public health concern. Potential further topics for the *IARC Handbooks* on primary prevention include a re-evaluation of the preventive effects of aspirin and sunscreens, in light of new evidence on their cancer preventive effects on colon cancer and skin cancer, respectively, and first-time evaluations of the potential preventive effects of vitamins B and D. In addition, IARC plans to evaluate and publish a IARC Handbook on screening for prostate cancer and lung cancer".

- → As planned in the MTS 2021–2025, so far IARC has published two *IARC Handbooks* volumes, providing evaluations and evidence-based recommendations on cervical cancer screening (Volume 18, in 2022) and oral cancer prevention (Volume 19, in 2023). The first volume of a two-part *IARC Handbooks* (Volume 20A: Reduction or Cessation of Alcoholic Beverage Consumption) has also been completed.
- → The IARC Handbooks programme has published Special Reports in the New England Journal of Medicine, summarizing the outcomes of the meetings on cervical cancer screening (Volume 18), oral cancer prevention (Volume 19), and reduction or cessation of alcoholic beverage consumption (Volume 20A).
- → Re evaluations of aspirin and of sunscreens, first-time evaluations of vitamin D and vitamin B, and screening of prostate cancer were not covered during the current MTS and may be part of the MTS 2026–2030.

# Main challenges and future perspectives

#### Challenges

- The programme aims to publish three IARC Handbooks volumes and the corresponding NEJM Special Reports in the next 5 years. Producing one volume per year, as initially planned in 2014, would require additional scientific staff. With the recruitment of one new staff scientist and additional visiting scientists, the programme may now be better positioned to support this ambitious goal.
- The programme requires different sets of expertise, because of the diversity of the topics covered by the IARC Handbooks. This creates a challenge to recruit the appropriate experts for each volume.
- Another challenge for the programme is the dissemination of outcomes and the translation of *IARC Handbooks* results into public health recommendations.
- The programme has just completed publication of a two-part volume on alcohol control: Volume 20A on Reduction or Cessation of Alcoholic Beverage Consumption and Volume 20B on Alcohol Control Policies. This recent experience with Volume 20B may be used by the programme to consider the pros and cons of such approaches in the future. If so, it should be conducted in close coordination with WHO headquarters.



- Health economics and cost-effectiveness are not addressed in the IARC Handbooks, although such approaches would be an added value to the product. Other suggestions would be to integrate information such as co-exposures, attributable risk fractions, and evidence gaps.
- Improved dissemination and coordination with WHO, governments, and other stakeholders are needed to influence cancer control policies. Establishing a comprehensive database of target audiences, including scientific and public health communities, policy-makers, and the media, could enhance outreach efforts.

#### Perspectives

- → In 2025-2026, the programme will develop an IARC Handbooks volume on lung cancer screening, reflecting its growing importance and recent advancements. Lung cancer, with the highest cancer mortality rate globally, has been highlighted by the European Council for potential population-level screening. Leveraging IARC's expertise in evaluating screening methods, this IARC Handbooks volume will collaborate with the EPR Branch and the CanScreen5 programme to enhance screening strategies, especially in LMICs.
- → An IARC Handbooks volume on gastric cancer prevention is planned for 2026-2027, focusing on LMICs. It will address primary prevention (reducing Helicobacter pylori exposure) and secondary prevention (screening). Funding negotiations for these IARC Handbooks volume are ongoing.
- → The implementation of the new Standard Operating Procedures between IARC and WHO should contribute to the reinforced collaboration with WHO headquarters and regional offices.

#### For more details

- → IARC Handbooks of Cancer Prevention website
- <u>Publications</u>
- Video on the IARC HandbooksThe IARC perspective on oral cancer prevention, N Engl J Med, 18 October 2022
- The IARC perspective on <u>alcohol reduction or cessation</u> and cancer risk, N Engl J Med. <u> 28 December 2023</u>



# World Code Against Cancer Framework

Case study

# **Overview of the project**

#### Objectives and target audience

The main goal of the WCACF is to provide a framework to develop Regional Codes Against Cancer that would include targeted evidence-based recommendations to raise awareness about risk factors and available effective

#### **Summary**

The World Code Against Cancer Framework (WCACF) is a global initiative led by IARC to provide evidence-based recommendations aimed at reducing cancer risk and death worldwide by defined regions of the world. It builds on the European Code Against Cancer (ECAC), which has been successful in translating scientific knowledge about cancer prevention into practical actions for individuals. The WCACF extends this approach globally, underpinned by a common rigorous methodology, to account for regional differences in cancer risk factors, disease patterns, and health systems, and adds recommendations for policy-makers.

The WCACF's recommendations focus on key preventive behavioural actions, environmental factors, and effective medical preventive interventions. These recommendations aim to empower individuals with evidence-based, clear, authoritative guidance to reduce their cancer risk or detect cancer early, while guiding policy-makers to implement or enact enabling structural policies.

preventive interventions, to communicate the current state of the science and, as a consequence, empower the individuals and the community of a given region of the world to make informed choices about their health. In addition, Regional Codes will complement these recommendations by providing guidance on the policies that need to be implemented to enable the individuals to comply with them. Its key objectives include:

- → Promote cancer primary prevention: The Regional Codes provide actionable advice to educate individuals to reduce their cancer risk through lifestyle changes and avoiding or reducing exposure to environmental risk factors.
- → Support early detection and screening: Regional Codes emphasize the importance of participating in cancer screening programmes where available, which can lead to early detection and better outcomes for several cancer types.
- → Guide public health policies: Regional Codes now include specific recommendations for policymakers to serve as a guide to develop, implement or enact policies that will enable healthy environments and healthy systems.

The recommendations from the different Regional Codes are targeted to different audiences, focusing mainly on individuals but also now targeting specifically policy-makers, providing a framework for cancer prevention policies and programmes. In addition, supplementary knowledge translation outputs are designed for front-line health-care professionals, and the scientific justifications of the recommendations are directed toward the research community in detailed peer-reviewed publications, thereby supporting evidence-based decision-making and further research.

#### History and evolution

The WCACF was launched by IARC in 2022 to expand the European initiative (ECAC), which had existed for several decades, to a more global framework aimed at reducing cancer incidence and



mortality through lifestyle and environmental changes and effective preventive interventions such as vaccination and screening. Its roots trace back to the ECAC 1st edition, published in 1987, IARC as institution only joined in 2014 at the 4<sup>th</sup> edition. Launched by the European Commission, the ECAC aimed to provide evidence-based recommendations for individuals to reduce cancer risk and death. Initial guidelines focused on lifestyle changes, such as smoking cessation, diet, physical activity or having a cervical smear and mammography regularly.

The ECAC underwent several updates, incorporating new scientific evidence and addressing emerging risks. Subsequent editions were released in 1994, 2003, and 2014, each time expanding and refining the recommendations to reflect new evidence. For instance:

- → The 1994 edition included recommendations on workplace exposures and radon.
- → The 2003 edition introduced more specific guidelines on diet, alcohol consumption, and sun exposure.
- → The 2014 edition, developed by a large panel of European experts under IARC's coordination, consisted of 12 recommendations covering a broader range of topics, including vaccination against cancer-causing viruses such as HPV, reducing alcohol intake, and participating in cancer screening programmes.

The success of the ECAC and the Agency's global mandate inspired IARC to provide a common framework and methodology to develop Regional Codes Against Cancer adapted to the needs of different regions of the world and their corresponding audiences, leading to the establishment of the WCACF. The aim is to extend the evidence-based recommendations to regions outside the European Union (EU), including LMICs, where cancer prevention resources and public health policies may differ significantly from those in HICs.

The first regional adaptation outside the EU was the Latin America and the Caribbean Code Against Cancer, 1<sup>st</sup> edition (LAC Code), launched in 2023, which addresses the unique epidemiological and socioeconomic situation of the region. The LAC Code featured 17 recommendations for the general public, accompanied by 17 recommendations for policy-makers to support public adoption.

The WCACF continues to evolve, with refinement of the methodology and efforts in planning the future development of the Asian Code Against Cancer (ACAC). This initiative involves collaboration among the Asian National Cancer Centers Alliance (ANCCA) members from 21 countries. The primary goal is to create region–specific cancer prevention recommendations that reflect the unique cancer burdens, risk factors, and public health infrastructures across Asia (see VIII. 2. Perspectives).

Other ongoing developments include the 5<sup>th</sup> edition of the ECAC (ECAC5), initiated in 2022 and to be launched in 2025, focusing on updating recommendations and integrating population-level prevention measures. The initiative also leverages digital platforms, such as online resources and interactive tools, to enhance accessibility and dissemination globally (see next section).

#### Methodology and tools

The methodology and tools behind the WCACF involve a multi-layered approach, combining targeted systematic evidence review, expert scientific assessment, public engagement, and innovative dissemination strategies. The following structured framework initially developed for the ECAC 4<sup>th</sup> edition serves as a foundation for adapting evidence-based cancer prevention recommendations to meet the unique needs of different regions while maintaining a unified strategy across all Regional Codes. The recommendations are developed by several working groups of independent experts from a given region, who evaluate the evidence on lifestyle factors (environmental exposures, infections and related interventions, cancer screening, and other relevant areas). When necessary, the working groups request targeted systematic reviews of the latest evidence to respond to a specific research question. This process involves evaluating

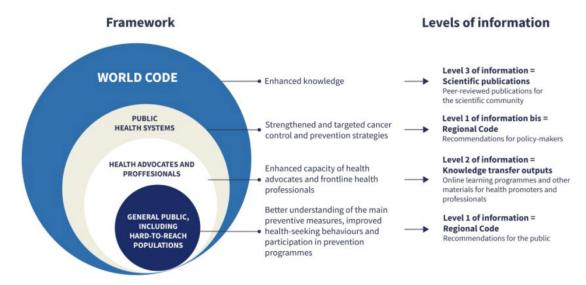


studies. After reviewing the evidence, the expert panel engages in an iterative consensus-building process. This involves multiple rounds of discussions, voting, and revising recommendations to ensure that they accurately reflect current scientific consensus. In addition, a working group on communication and health literacy advises on how to clearly communicate the science to a lay audience and performs an evaluation study in the general public of the region to test the draft recommendations. Experts are expected to work independently, basing their contributions solely on their professional expertise rather than the views or positions of any affiliated organization. In addition, they must disclose any actual or potential conflicts of interest relevant to the topic under discussion.

A Scientific Committee representing major national cancer institutes or governmental organizations of the region reviews and approves the recommendations, ensuring broad support from the most authoritative sources. An Advocacy Group composed of representatives from leading cancer prevention and control organizations and networks in the region plays a key role in supporting the implementation, dissemination, and impact of the corresponding Regional Code.

Under the WCACF, each Regional Code is structured according to the following three levels of information:

- Level 1, Region-specific recommendations: The methodology acknowledges that a one-size-fits-all approach is not practical for global cancer prevention. Instead, the WCACF is adapted to reflect each region's unique epidemiological profile, socioeconomic and cultural context, and health-care infrastructure. Recommendations are presented in two sets of recommendations: one in a clear format suitable for individuals, and another one targeted to policy-makers.
- Level 2, Knowledge translation outputs for target groups: The detailed rationale of the
  recommendations is expanded under targeted outputs, such as training materials for health
  professionals, policy briefs for decision-makers, and educational content for the public. These
  knowledge translation outputs aim to provide detailed explanations and contextual guidance
  on cancer prevention strategies.
- Level 3, Publication of scientific justification: The underlying scientific evidence supporting
  each recommendation is published in peer-reviewed journals. These articles are aimed at the
  scientific community and contain detailed explanations of the methodologies used to develop
  the recommendations.



World Code Against Cancer Framework. 63

<sup>63</sup> https://cancer-code-world.iarc.who.int/methodology/



Each Regional Code has a dedicated website, such as the European Code Against Cancer<sup>64</sup> and the LAC Code<sup>65</sup>. These platforms provide comprehensive resources, including detailed explanations of each recommendation, evidence summaries, training modules, and additional support materials for health professionals. Feedback from a wide range of stakeholders, including healthcare professionals, policymakers, public health agencies, and patient advocacy groups, is solicited during the process of developing a given Regional Code.

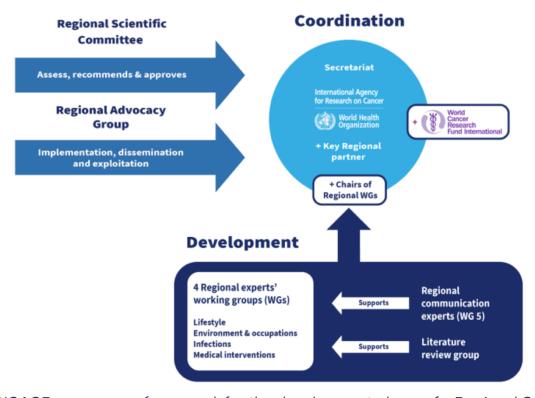
The ongoing development of the ECAC5 is closely linked with the development of innovative tools such as the BUMPER (Boosting the Usability of the EU Mobile App for Cancer Prevention) project, an app that will extend the reach of the European Code Against Cancer's recommendations, making them accessible to broader and more diverse populations.

Finally, the WCACF includes competency-based training programmes for health-care professionals, hosted on platforms such as the PAHO Virtual Campus for Public Health. These programmes aim to equip specifically primary health-care workers with the necessary knowledge to implement the cancer prevention recommendations effectively.

#### **Structure**

#### Governance framework

The governance framework of the WCACF involves collaboration among multiple stakeholders, including international organizations, regional bodies, expert committees, and public health institutions, which are key to ensuring the Regional Code's success and relevance in the region of interest (see I. Overview of the project, 3. Methodology and tools).



WCACF governance framework for the development phase of a Regional Code.66

<sup>64</sup> https://cancer-code-europe.iarc.fr/ 65 https://cancer-code-lac.iarc.who.int/en/ 66 https://cancer-code-world.iarc.who.int/methodology/



Multidisciplinary advisory panels, including experts in cancer epidemiology, cancer prevention, public health, behavioural science, and health communication, are established to guide the development and periodic revision of the recommendations.

#### International collaborative network

The WCACF involves experts from across the region, with IARC acting as coordinator and secretariat, creating a broad network of specialists.

The project to develop ECAC5 involves about 80 regional experts distributed in 5 working groups, the Scientific Committee, the Advocacy Group, and the IARC Secretariat in a multidisciplinary collaborative effort:

- → Coordination group for development and maintenance:
  - Secretariat: IARC:
  - Chairs of the Experts Working Groups: Working Group 1 (Lifestyle Determinants): Imperial College London; Working Group 2 (Environmental and

Occupational Determinants): Utrecht University; Working Group 3 (Infections): Centro di Riferimento Oncologico (CRO), Italy; Working Group 4 (Medical Interventions): Erasmus University Medical Center, Netherlands; Working Group 5 (Communication and Health Literacy): University of Cambridge, UK;

o Representatives: World Cancer Research Fund International (WCRF).

#### → Scientific Committee:

- o National Institute of Public Health (NIJZ), Slovenia
- o Italian National Institute of Health (ISS), Italy
- Karolinska Institutet, Sweden
- French National Cancer Institute (INCa), France
- o Maria Sklodowska-Curie National Research Institute of Oncology, Poland
- o University of Valencia, Spain
- o Netherlands Cancer Institute (NKI), Netherlands
- National Cancer Registry Ireland
- National Institute of Oncology, Hungary
- o Oncology Institute Prof. Dr I. Chiricuta, Romania
- World Health Organization (WHO), Switzerland
- o German Cancer Research Center (DKFZ), Germany
- Danish Cancer Society Research Center

More than 60 experts across Latin America and the Caribbean were involved in the development of the first LAC Code:

- → Coordination group for development and maintenance:
  - Secretariat: IARC, PAHO/WHO
  - Chairs of the Experts Working Groups: Instituto Nacional de Salud Publica, Mexico; Advanced Center for Chronic Diseases (ACCDiS), Chile; Agencia Costarricense de Investigaciones Biomedicas; Fundacion INCIENSA (ACIB-FUNIN), Costa Rica; Facultad de Ciencias Sociales de la Universidad de los Andes, Colombia; WHO headquarters,

#### **Links with WHO**

For the LAC Code, the Pan American Health Organization (PAHO/WHO) works together with the IARC secretariat and is the key regional partner to coordinate the dissemination and implementation of the LAC Code in Latin American and the Caribbean (see II. Structure, 1. Governance framework).

For ECAC, whereas the key regional partner is the European Commission, WHO plays crucial roles in two different capacities: WHO headquarters as part of the Scientific Committee, and the WHO Regional Office for Europe as part of the Advocacy Group, fundamental for the dissemination and implementation in the EU region.



- → Scientific committee:
  - o Instituto Nacional de Cancer Jose Alencar, Brazil
  - Centro de Estudios de Estado y Sociedad (CEDES/CONICET)/Consejo Nacional de Investigaciones Científicas y Tecnicas, Argentina
  - o Universidad Peruana Cayetano Heredia, Peru
  - o Instituto de Nutricion y Tecnologia de los Alimentos, Universidad de Chile, Chile
  - o Instituto Nacional de Cancerologia, Mexico
  - o Centro Javeriano de Oncologia Hospital Universitario San Ignacio, Colombia
  - o Centro Hemato-Oncologico Panama, Panama
  - o Universidad de Puerto Rico, Puerto Rico

Involvement of scientific organizations, cancer leagues, and patient associations ensures effective dissemination and advocacy (see III. Global reach and impact, 3. Advocacy). In addition, ECAC5 is a priority set in the Europe's Beating Cancer Plan<sup>67</sup>, launched by the European Commission in 2021. The European Plan explicitly mentions ECAC and its prevention priorities "SAVING LIVES THROUGH SUSTAINABLE CANCER PREVENTION" were partly inspired by ECAC, according to the Member of the European Parliament Professor Véronique Trillet-Lenoir, responsible for defining the Parliament's position on the EU Cancer plan.

#### Resources

Funders for the ECAC:

- → European Commission: ECAC5 received €1 500 000 through the EU4Health programme for revising and updating the ECAC. An additional €81 063.20 was allocated for the BUMPER project in 2022.
- → IARC contributed €1 000 000.
- → Cancer Prevention Europe (CPE) contributed funding of a formative research study for ECAC5 and health promoters training on ECAC4.

#### Funders for the LAC Code:

- → The American Cancer Society (ACS) provided US\$30 000 (2018–2022) for formative research for the LAC Code.
- → Sociedade Beneficente Israelita Brasileira Albert Einstein contributed €257,594.80 to support the development of the LAC Code in 2020–2024.
- → IARC contributed with a large among.
- → A memorandum of Understanding (MoU) is established with PAHO/WHO to support cancer prevention efforts in Latin America and the Caribbean.

IARC staff working in the WCACF programme include two P-Staff Scientists and one ECVS funded by Bumper, as well as the contribution of the ENV Branch Head.

# **Global reach and impact**

#### Impact on public health policies and guidelines

The WCACF builds on the successful ECAC model while following a common and rigourous methodology to address regional differences in cancer patterns, risk factors, and healthcare infrastructure to develop Regional Codes Against Cancer. Regional ownership and support from local cancer prevention leaders and institutions enhance acceptance and implementation, helping to reduce disparities in cancer outcomes globally.



Some adaptations have tailored the recommendations to align with local conditions, including cultural, dietary, and health challenges. For example, recommendation No. 12 of the LAC Code includes testing for and treating Helicobacter pylori, a known risk factor for stomach cancer.

The WCACF supports governments in integrating cancer prevention strategies into national health policies, aligning efforts with the 2017 World Health Assembly resolution on cancer prevention and control<sup>68</sup>.

Cancer remains a significant health challenge in the European Union. Supporting the goals of Europe's Beating Cancer Plan , the ECAC aims to mitigate this burden by providing evidence-based recommendations that could prevent approximately 40% of cancers if implemented effectively. The ECAC's guidelines focus on major risk factors like tobacco use, which accounts for nearly 20% of the cancer burden, along with lifestyle factors such as diet, alcohol consumption, physical inactivity, and occupational or environmental exposures.



- 1 Do not smoke. Do not use any form of tobacco.
- 2 Make your home smoke free. Support smoke-free policies in your workplace.
- 3 Take action to be a healthy body weight.
- 4 Be physically active in everyday life. Limit the time you spend sitting.
- 5 Have a healthy diet:
  - · Eat plenty of whole grains, pulses, vegetables and fruits.
  - · Limit high-calorie foods (foods high in sugar or fat) and avoid sugary drinks.
  - · Avoid processed meat; limit red meat and foods high in salt.
- 6 If you drink alcohol of any type, limit your intake. Not drinking alcohol is better for cancer prevention.
- 7 Avoid too much sun, especially for children. Use sun protection. Do not use sunbeds.
- 8 In the workplace, protect yourself against cancer-causing substances by following health and safety instructions.
- 9 Find out if you are exposed to radiation from naturally high radon levels in your home. Take action to reduce high radon levels.
- 10 For women:
  - · Breastfeeding reduces cancer risk. If you can, breastfeed your baby.
  - Hormone replacement therapy (HRT) increases the risk of certain cancers.
     Limit use of HRT.
- 11 Ensure your children take part in vaccination programmes for:
  - · Hepatitis B (for newborns)
  - · Human papillomavirus (HPV) (for girls).
- 12 Take part in organized cancer screening programmes for:
  - · Bowel cancer (men and women)
  - · Breast cancer (women)
  - · Cervical cancer (women).

The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer. Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

Find out more about the European Code Against Cancer at: http://cancer-code-europe.iarc.fr

This project is co-financed by the European Union and coordinated by the specialized cancer agency of the World Health Organization, the International Agency for Research on Cancer.

International Agency for Research on Cancer



The European Code Against Cancer, 4th edition69.



The upcoming 5<sup>th</sup> edition (ECAC5) will serve as a key tool for achieving the objectives of Europe's Beating Cancer Plan. It will revise the recommendations using updated scientific evidence and incorporate synergies with other noncommunicable disease (NCD) strategies. A special focus will be placed on addressing social inequalities in health to enhance cancer prevention.

Similarly, the 17 recommendations of the LAC Code are not legally binding but serve as a valuable resource for governments to implement cancer control strategies in line with international consensus on prevention.

#### Advocacy

The WCACF is supported by comprehensive public health campaigns that leverage various channels, including social media, traditional media, and community outreach, to raise awareness about its recommendations.

In addition, training and educational resources are provided for healthcare professionals, educators, and policymakers. These materials are designed to equip them with the knowledge and tools necessary to effectively communicate the WCACF 's recommendations and integrate cancer prevention strategies into their practices. The training resources include workshops, webinars, and informational guides that focus on evidence-based cancer prevention methods.

The BUMPER project (see I. Overview of the project, 3. Methodology and tools) aims to modernize and enhance the dissemination of cancer prevention recommendations in the EU through digital technology by promoting a mobile app to extend the reach of the recommendations. Through its digital approach, the project aims to empower individuals with practical tools and information for making informed health decisions.

# **Interface with other Pillars and Branches**

The WCACF draws on all of IARC's work for its scientific foundation, with key initiatives like the *IARC Monographs, IARC Handbooks*, studies on attributable fractions, and etiological research informing the recommendations.

Pillar 1	Pillar 2	Pillar 3	Pillar 4
The work of CSU on attributable fractions is integrated into the WCACF during the assessment of the epidemiological situation of a given region (planning phase).	Etiological research, through systematic reviews of the evidence, contributes to the foundation of the Regional Codes' recommendations on primary prevention by informing the identification of key environmental and lifestyle determinants of cancer (development phase).	ENV leads the WCACF initiative methodology, fundraising, planning of new Regional Codes, and conducting formative and evaluation-of-impact research (planning, development, and implementation phases).  EPR contributes with a Senior Scientist as part of the IARC Secretariat advising on cancer screening. EPR research contributes to the foundation of	The IARC Monographs provide evidence- based evaluations of carcinogenic risks, and the IARC Handbooks offer guidance on cancer preventive interventions.  The IARC Monographs and the IARC Handbooks are key authoritative sources of the information and a fundamental part



the Regional Codes' recommendations on infections and screening.	on the methodological process to develop a Regional Code.
	LCB has supported the ECAC4 related training and has liaised with the PAHO Virtual Campus for Public Health.

# **Key Performance Indicators (KPIs)**

Although the WCACF does not have a formal set of KPIs, its implementation should be monitored by evaluating the adoption of recommendations across various populations and measuring their impact on cancer-related outcomes in the long run. This process should involve using surveys to gauge public awareness and adherence, analysing health data to track changes in cancer incidence and risk factors, and gathering feedback from stakeholders to assess the effectiveness of the Regional Codes' dissemination and impact.

An evaluation study<sup>70</sup> was conducted in 2021 to assess the impact of the ECAC 4<sup>th</sup> edition. The study aimed to measure various KPIs to understand the Code's effectiveness in promoting cancer prevention. The methodology included the following components:

- Online survey in the general public: A survey was administered targeting adults across eight European countries. It included questions about awareness, familiarity, and intentions to change behaviour related to the ECAC4 recommendations. The survey data were analysed by age, gender, and country, providing both descriptive statistics and adjusted logistic regression analyses to identify significant patterns and associations. KPIs measured included: Awareness of cancer prevention guidance: 70% of respondents indicated awareness of general cancer prevention guidance.
- Familiarity with the ECAC: Awareness of the ECAC itself varied significantly by country, from 2% in the UK to 21% in Hungary and Poland, highlighting a gap in recognition despite the long-standing promotion.
- Behavioural change intentions based on gender: Female respondents showed a higher likelihood of adopting lifestyle changes to reduce cancer risk compared with males, pointing to gender-specific responses to cancer prevention messaging.
- → Semi-structured interviews with professionals from cancer leagues: Twenty-eight health promotion professionals from not-for-profit organizations were interviewed, covering 25 European countries. The interviews aimed to explore the use of the ECAC in professional practices, the methods of dissemination, and any regional variations in promoting cancer prevention.
- → The evaluation showed that although general awareness of cancer prevention is relatively high, familiarity with the ECAC remains low among the general public. Professionals frequently use the ECAC to inform public health initiatives. The evaluation highlighted the need for better public dissemination strategies and more robust mechanisms for tracking the ECAC's influence on health behaviours and policy (see VIII. Main challenges and future perspectives).
- → Systematic approaches to measuring Regional Codes impact in each corresponding region is needed.

<sup>70</sup> https://pubmed.ncbi.nlm.nih.gov/33611135/



# **Alignment with IARC MTS 2021-2025**

### Contribution to IARC's mission

**Involvement in the creation and development of collaborative networks:** "IARC will increasingly partner with relevant regional organizations to further advance high-quality diagnostic practice for cancer pathology and research.<sup>71</sup>"

→ The WCACF engages a diverse group of experts from across each region, extending beyond IARC to include specialists from public institutions, academia, civil society organizations, and funding and private organizations, such as WCRF, FISABIO - Portuguese League against Cancer, or the Hungarian League against Cancer for the BUMPER project. This approach fosters a comprehensive network of stakeholders (see II. Structure).

Knowledge mobilization and capacity-building: "IARC will ensure that relevant cooperation activities are conducted in a balanced manner across all continents and regions.<sup>72</sup>" The WCACF provides training and educational resources for health promotion experts, health-care professionals, and policymakers to equip them with the skills needed to communicate evidence-based cancer prevention strategies effectively. Specific examples include:

- → The development by IARC of a <u>40-hours accredited training programme</u>,
- → The development by IARC with support of CPE, of a <u>5-hours training programme</u>.

Impact on the development of public health policy, national or international guidelines and recommendations: Positioning IARC "as a leading authority on global cancer prevention research<sup>73</sup>"

→ By developing a transferable framework for applicable cancer prevention to worldwide, IARC establishes itself as a leading authority in cancer prevention research. The WCACF acts as a key tool for policymakers by providing scientifically recommendations that guide the development implementation of effective prevention strategies. This framework supports the integration of evidence-based measures into national health plans (see III. Global rearch and impact, 2. Impact on public health policies and guidelines).

# Achievements of assigned objectives

Updates and development of Regional Codes: "Pertinent evidence generated through the abovementioned research will inform the development

and evaluation of region-specific Codes Against Cancer (...) with a focus on updating the European Code Against Cancer and developing the first Code Against Cancer for Latin America and the Caribbean.<sup>74</sup>"

→ The LAC Code has been finalized with region-specific recommendations. Four thematic working groups - Lifestyle, Environmental and Occupational Risks, Infections and Vaccination,

# Integration into the IARC Project Tree

The WCACF integrates into the IARC Project Tree by contributing to multiple strategic objectives:

- Level 2 Objective: The WCACF supports Level 2 Objective #3, "Evaluating cancer prevention interventions."
- Level 3 Objectives:
- Objective 3.1: "Enhance understanding of evidence-based interventions for cancer prevention and control to support their practical application, including those related to cancer disparities"
- Objective 3.2: "Enhance understanding of the efficacy and effectiveness of population-based interventions and cancer prevention programmes."

<sup>71</sup> IARC Medium-Term Strategy 2021-2025, p.10.

<sup>72</sup> lbid., p.17.

<sup>73</sup> Ibid., p.10.

<sup>74</sup> Ibid., p.37.



and Medical Interventions - produced 17 recommendations of the general public and 17 recommendations for policymakers that reflect regional conditions and health priorities.

- The LAC Code content development included a pilot communication study in five countries (Colombia, Brazil, Peru, Puerto Rico, and Chile) to test the draft recommendations.
- A 40-hour accredited competency-based microlearning programme for primary healthcare professionals was developed in Spanish to complement the recommendations. This knowledge translation output (Level 2 of information) in the form of a comprehensive training programme on cancer prevention includes interactive online modules corresponding to each of the recommendations, communication between the health-care professional and the patient, and other topics of interest. Portuguese and English translations are under way.
- Scientific manuscripts justifying each recommendation have been published in the journal Cancer Epidemiology, contributing to Level 3 information.
- o Targeted systematic reviews conducted by the literature review group informed the recommendations.
- Two executive meetings in São Paulo (May and November 2022) involved the Scientific Committee, WG chairs, and the Advocacy Group to assess and approve the recommendations. High-level meetings ensured collaboration and consensus across different expert groups.
- Multiple Zoom meetings and teleconferences took place between the Secretariat and the WGs, addressing specific aspects of the project and coordinating the education subgroup to produce the online training.
- The IARC Secretariat coordinated all the processes and designed and developed the competency-based microlearning programme and is a co-author of all scientific publications.
- → The fifth edition of the ECAC (ECAC5) was kicked off in 2022, with several key milestones achieved ahead of its launch in 2025:
  - Multiple expert groups have been working on the review of the evidence and the drafting of the updated recommendations, focusing on the latest scientific evidence. An evaluation study on the communication has been performed in more than 10000 people from 10 EU countries to inform the ECAC5.
  - The scope of ECAC5 has been broadened beyond individual advice to include systemic prevention strategies, addressing social determinants of health and promoting policies to reduce cancer risks.
  - Recommendations have been harmonized with broader non-communicable disease prevention strategies, ensuring consistency across health initiatives and addressing health inequalities.
  - Ongoing consultations are being conducted to refine the dissemination plan, targeting diverse audiences, including hard-to-reach populations.
  - A framework for systematic evaluation is underway, depending on external funding, to measure the impact of the ECAC5 on public health outcomes.
  - Final recommendations have been approved by late 2024, after a rigorous review process by the Scientific Committee.
  - o Translations of all outputs in Level 1 (the ECAC5 recommendations for the general public and for policymakers) and Level 2 into all EU languages will be carried out in early 2025.

# Main challenges and future perspectives

# Challenges

• Cultural and regional adaptation: Adapting the Regional Codes' recommendations to align with specific cultural, social, and regional contexts poses a significant challenge.



Recommendations may need tailoring to accommodate cultural beliefs, dietary habits, and local policy environments. For example, dietary guidelines should reflect local foods and practices, and alcohol-related recommendations may need to consider cultural norms where alcohol plays a significant social role. Using the methodology under the WCACF, regional adaptations may involve adding, dropping, or modifying recommendations based on the scientific evidence relevant for the region, local prevalence of risk factors, health-care infrastructure, and policy landscape. Some recommendations from the ECAC, such as the one on radon, may not be relevant in all regions. Conversely, other regions may face unique exposures, like the consumption of very hot drinks (e.g. maté in South America), which would warrant specific guidance. Recommendations on preventive medical interventions such as test-and-treat or cancer screening need to be tailored to the health systems reality of different regions of the world.

- High costs of expansion: Expanding the WCACF to new regions entails significant investment, as seen with the initial ECAC. Moving to different areas requires substantial funding to scientifically assess the situation of the region and map risk factors and infrastructure, review the evidence to adapt the recommendations according to the experts' assessments and discussions held during intensive meetings, engage local stakeholders, and ensure successful implementation and evaluation. In addition, many LMICs struggle with limited health-care infrastructure and resources, hindering the effective implementation of cancer prevention strategies. Access to health care, early detection services, and public health initiatives may be inadequate, which can limit the reach and sustainability of lifestyle changes and awareness efforts. In addition, mobilizing resources for public education campaigns in these settings can be challenging, making it difficult to disseminate the WCACF's messages effectively.
- Low awareness and dissemination in the EU: Evidence indicates that the recommendations of the ECAC are only partially reaching the population, with awareness currently about 10% in Europe (see V. KPIs). The Europe's Beating Cancer Plan aims for at least 80% awareness by 2025, necessitating significant efforts to increase cancer prevention literacy. Current dissemination largely relies on governments and cancer leagues, and implementation varies across countries, with Poland and Hungary showing the most progress. Effective dissemination requires country-specific translation into local languages and government-led implementation. In addition, while the BUMPER project focuses on using a mobile app to disseminate the ECAC, studies from Europe and Latin America suggest that apps alone are insufficient for achieving behaviour change and adherence to preventive interventions. Behavioural change interventions require tailored strategies for each topic, and simply providing information through digital platforms may not effectively alter health behaviours. This highlights the need for dedicated efforts in behavioural change science and targeted interventions to complement digital tools.

# Perspectives

- → ECAC 5<sup>th</sup> edition: The ECAC5 (See I. Overview of the project, 3. Methodology and Tools) is scheduled for submission to the European Commission in early 2025, followed by a formal launch in October 2025. The final project deliverables are expected by June 2026.
- → Expansion of Regional Codes: Beyond the EU and Latin America, there are plans to develop Regional Codes for various regions, depending on the external funding available (e.g. Asia, Middle East, Africa). In the case of Asia, IARC presented the WCACF at the 2<sup>nd</sup> ANCCA Annual Scientific Conference in Singapore on 2–3 November 2023, marking a significant step to raise awareness of the need for an ACAC, potentially divided into sub-Codes by subregions. IARC has established a Memorandum of Understanding (MoU) with Japan to explore further collaboration, although funding is still required to start the project. A virtual scoping meeting in September 2023 initiated discussions on key elements to be included in a future ACAC.



→ Enhancing evaluation and dissemination: After the evaluation study (see V. KPIs) that revealed limited public dissemination, subject to external funding, future ECAC editions will include structured evaluations to assess the societal impact and guide updates. The evaluation

underscored the need for improved dissemination strategies and robust mechanisms for tracking the WCACF's influence on health behaviours and policy changes. Enhanced dissemination efforts will aim to increase public awareness and engagement, helping to ensure that the recommendations included in the Regional Codes are more widely adopted and integrated into national cancer prevention strategies.

# For more details

- → WCACF website
- **→** ECAC website
- → LAC Code website



# CanScreen5 Case study

# **Overview of the project**

The collected data are published on the <u>CanScreen5 website</u>, a global repository of information on cancer screening programmes. These validated data, made publicly available through the portal, aim to support programme managers in cancer screening evaluation, benchmarking, quality improvement and informed policy formulation.

More than 90 participating countries reported data for breast, cervical or colorectal cancer screening programmes in the repository. Substantial observed regarding heterogeneity was programme organization and performance. Reported screening coverage in 2022 ranged from 1.7% (Bangladesh) to 85.5% (England, United Kingdom) for breast cancer, from 2.1% (Côte d'Ivoire) to 86.3% (Sweden) for cervical cancer, and from 0.6% (Hungary) to 64.5% (the Netherlands) for colorectal cancer screening programmes.

The data collected mainly come from the Ministry of Health in each country, thanks to a harmonized set of criteria and indicators. The strength of the CanScreen5 project is that the collected information is provided and validated by

programme coordinators and does not rely on secondary data sources.

# Summary

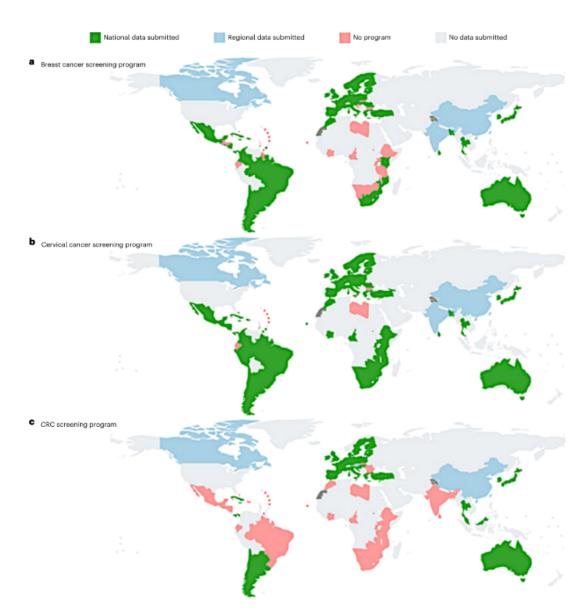
IARC reported the status and the performance of cancer screening programmes from EU Member States in 2008 and 2017. Such consecutive evaluations permit comparisons in the performance of screening programmes using a harmonized set of indicators. Outside the EU, cancer screening evaluation reports have only been published regularly in a few countries. Most LMICs have only been reporting screening coverage based on population surveys because of logistic, fiscal, and organizational challenges of data collection across the screening continuum.

Initiated in 2019, the IARC Cancer Screening in Five Continents (CanScreen5) project aims to collect information on the characteristics and performance of cancer screening programmes across the globe. The core objective of CanScreen5 is to encourage and support countries to collect and use cancer screening data for effective programme evaluation and quality improvement. This global project gathers cervical, and colorectal cancer (CRC) screening programmes in a standardized manner using an online portal. This global initiative gathers cancer screening performance data beyond screening coverage and encourages programmes to estimate key performance indicators covering entire screening pathways.

The collected data are published on the CanScreen5 website, a global repository of information on cancer screening programmes. These validated data, made publicly available through the portal, aim to support programme managers in cancer screening evaluation, benchmarking, quality improvement, and informed policy formulation.

In order to improve the quality and impact of cancer screening programmes, the CanScreen5 project engaged directly with screening programme managers and trained them to submit information from their own programmes related to the essential criteria identified by the IARC expert group. With the help of global experts, CanScreen5 also listed and defined key indicators to measure performance and outcome across the screening continuum (see KPIs below). Countries with data from the programmes are assisted to estimate these KPIs, and the validated results are published on the website.





The status of data collection for the CanScreen5 project from various countries for breast cancer, cervical cancer, and colorectal cancer screening programmes in September 2022.

# **Structure**

### Governance framework

The governance of the CanScreen5 programme is based on three main bodies. The Advisory Board gathers 21 experts coming from the 5 continents. The Scientific Committee consists of 15 international experts in the field of cancer control, also representing the 5 continents.

IARC is in charge of the Secretariat and the coordination of the project, with Dr Partha Basu (Head of the EPR Branch) as PI. In addition, the IARC Ethics Committee reviewed the project and waived the requirement for any consent for collecting data. Data providers are mandated to ensure they have the necessary approvals from authorities to share data.



## International collaborative network

Other key partners of CanScreen5 include the American Cancer Society (ACS), Centre for Global Health Inequalities Research (CHAIN), Centro di Riferimento per l'Epidemiologia e la Prevenzione Oncologica in Piemonte (CPO), Association of European Cancer Leagues (ECL), Friends of Cancer Patients (FOCP), Medical Research Council, United Kingdom (MRC), International Federation of Cervical Pathology and Colposcopy, Union for International Cancer Control (UICC), and Islamic Development Bank through Gulf Cancer Council. Data collection from Europe was supported through a grant from the European Commission.

# **Links with WHO**

The CanScreen5 programme has established a close cooperation with WHO, especially at regional level with the WHO Regional Office for Africa, the WHO Regional Office for Europe, and the WHO Regional Office for the Americas. At this stage, there is a little interaction with WHO headquarters regarding CanScreen5.

### Resources

This project was initially funded by IARC and by the European Commission for the preparation of the European Cancer Screening Report 2017. The training platform was partially sponsored by the American Cancer Society (ACS), National Cancer Institute (NCI-US), Medical Research Council (MRC-UK), and WHO Regional Office for Europe (WHO/Europe). The programme also benefits from support of the European Union Joint Research Centre (JRC), Centre for Global Health Inequalities Research (CHAIN), Union for International Cancer Control (UICC), and the Norwegian Government. Recently the project has obtained funding from the Islamic Development Bank.

These resources are mainly dedicated to the website and the organization of the training sessions on quality management. Each training session includes 20 countries in the Americas, Europe, or Africa and costs about €70 000. It is based on a hybrid format with webinars and face-to-face workshops. The training materials are available on the IARC Learning platform. No money is transferred to the participating countries as part of this project.

Ten employees of the Agency are involved in this project, mainly from the EPR Branch, including Dr Partha Basu, Dr André Carvalho, Mr Eric Lucas, and Dr Mary Luz Rol. CanScreen5 also benefits from the competences of numerous screening experts worldwide.

# **Key Performance Indicators (KPIs)**

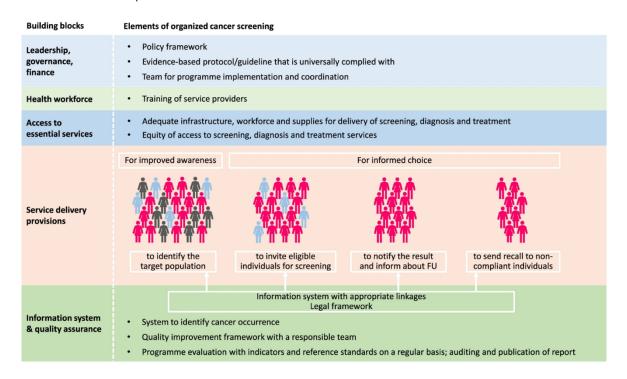
In 2022, an expert group led by the IARC team working on CanScreen5, including members of the advisory board, listed 16 criteria that need to be fulfilled for a screening programme to be considered as well organized:

- → Leadership, governance, and financing for cancer screening: A policy framework exists that describes the governance structure, programme objectives, financial resource allocation etc.; an evidence-based protocol and guideline exists; a team or organization is responsible for programme implementation, coordination, and protocol compliance.
- → Health workforce: Service providers are adequate in number, and they have adequate provision for training and periodic reorientation.
- → Access to essential services: Adequate infrastructure, workforce and supplies are available for seamless service delivery to all eligible individuals without causing financial hardships to them.
- → Service delivery: Provision is there for population education to improve awareness; screening, diagnostic, treatment and follow up services are provided following the protocol and guideline; a system is in place for invitation of the eligible population and recalling those requiring further assessment/treatment. Every individual has informed choice.



→ Information systems and quality assurance: A robust health information system with an appropriate legal framework exists so that it is capable of implementing invitation and call-recall and also capturing performance data for programme evaluation with full respect for privacy legislation and ethical and deontological concerns; a team or organization is responsible for implementing quality improvement using appropriate indicators and standards.

Through fulfilment of these criteria, screening programmes can ensure that any inherent harms are minimized and outweighed by the potential benefits at the population level. This approach is detailed in a dedicated publication, available online:



Building blocks for core elements of an organized screening programme<sup>75</sup>

# Alignment with IARC MTS 2021-2025

According to the IARC MTS 2021-2025, "IARC will evaluate means to address health system barriers to equitable and high-quality implementation of screening for cervical, breast, and colorectal cancer, in collaboration with national screening experts, in the framework of Cancer Screening in Five Continents (CanScreen5). This collaborative work will generate evidence on effectiveness of cancer screening from real programmatic settings. In addition, this work will identify quality gaps and help reduce access barriers due to economic or social factors".

→ IARC launched the CanScreen5 project to collect, analyse and disseminate information on cancer

# **Integration into the IARC Project Tree**

The CanScreen5 programme is part of Level 2 objective of the IARC Project Tree #3 "Evaluating cancer prevention interventions".

It contributes to the **Level 3 objectives**:

- → Objective 3.1: Enhance understanding of evidence-based interventions for cancer prevention and control to support their practical application, including those related to cancer disparities.
- → Objective 3.2: Enhance understanding of the efficacy and effectiveness of population-based interventions and cancer prevention programmes.

<sup>75</sup> Source: An international consensus on the essential and desirable criteria for an 'organized' cancer screening programme, BMC Medicine



screening programmes globally, and encourage and support countries to routinely collect screening performance data. Focusing on secondary prevention of cancer, as well as providing important tools and training for capacity building in LMICS, the CanScreen5 project is perfectly in line with the objectives of the MTS 2021-2025.

# Main challenges and future perspectives

# Challenges

The CanScreen5 project represents a major contribution for the development of cancer prevention in LMICs, but its development faces several challenges.

- Global reach: The original ambition of the project was to reach out to all countries and build a data repository as an IARC flagship programme, similar to the Global Cancer Observatory. However, at this stage of the project, CanScreen5 has collected data from a limited number of countries. The reasons for non-participation of some countries approached to join CanScreen5 include the voluntary nature of participation (no national or global mandate), non-availability of approval from higher authorities, and reluctance of programmes to share data because of the fear of receiving criticism for poor performance. As the project matures and published data become more visible, more countries should become part of this network. The PI of CanScreen5 identifies the extension of the project in the Middle East, in Africa (French-speaking countries), and in Asia as a priority (including the participation of China, India, and Indonesia).
- Quality of data: A new round of data collection from Europe will be initiated by IARC to update
  these data. Furthermore, the quantitative data from most LMICs is very incomplete. Sometimes
  programmes are reporting the number of examinations and tests performed and not the
  number of participants undergoing screening, which makes it difficult to exclude participants
  undergoing repeat testing within a short interval.
- Additional cancer sites: CanScreen5 is collecting screening data on three cancer sites for
  which screening is most prevalent. Two of these cancer sites correspond to the WHO global
  initiatives (breast and cervical cancers). However, as screening for other cancer sites becomes
  evidence-based and is implemented, for example, lung and prostate cancers, the project will
  have to include them as well.
- Quality assurance: large variability was observed regarding compliance with further
  assessment of screening programmes and detection rates reported for precancers and
  cancers. A concern is lack of data to estimate performance indicators across the screening
  continuum. This underscores the need for programmes to incorporate quality assurance
  protocols supported by robust information systems. Programme organization requires
  improvement in resource-limited settings, where screening is likely to be resource-stratified
  and tailored to country-specific situations.

# Perspectives

Additional perspectives for the CanScreen5 project deal with the following dimensions:

- → The consolidation of a "training-of-trainers model" to accelerate the dissemination of best practices.
- → The translation of the CanScreen5 website into Russian, to complement the versions in English, French and Spanish.
- → The promotion of open-source software such as DHIS2 already used by 120 countries, to facilitate the implementation of screening programmes and the collection of data by IARC.



- → The building of an interface between CanScreen5 and Globocan (or merging of the two websites), to provide a unified IARC online resource on cancer data.
- Some modelling to better understand the links between cancer screening and the decrease in cancer mortality, as well as the definition of an investment case to evaluate the return on investment of screening programmes (ROI of €1 on screening).

As explained in the Nature publication, the development of the CanScreen5 project is also dependent on the evolution of cancer screening programmes worldwide. Such programmes should "consider the following measures to improve data quality and completeness:

- Conduct a thorough assessment of services associated with screening based on the information and data available;
- Identify the essential criteria for organized programmes that are either missing or poorly implemented;
- Develop a feasible, measurable and time-bound plan in consultation with all stakeholders to improve the quality of services at different levels;
- Dedicate an adequate budget for quality assurance and put together a team responsible for implementing quality assurance, if not already in place;
- Build or strengthen information systems to capture performance data so that the quantitative data collection tools can be completed and KPIs can be estimated;
- Create links with population databases (e.g. electoral rolls or birth registers) to be able to identify screen-eligible individuals and with PBCRs to monitor impact;
- Leverage the vertical investments made to improve surveillance systems and mobile health applications to mitigate the COVID-19 pandemic;
- Invest in capacity-building of policy-makers, manager, and health professionals engaged in screening-related activities to be able to understand the value and application of quality assurance".

### For more details

- → CanScreen5 website
- CanScreen5 publication #1
- → CanScreen5 publication #2
- → CanScreen5 publication #3
- → <u>IARC Handbooks of Cancer</u> <u>Prevention (breast cancer)</u>
   → <u>IARC Handbooks of Cancer</u>
- IARC Handbooks of Cancer Prevention (colorectal cancer)
- → <u>IARC Handbooks of Cancer</u> <u>Prevention</u> (cervical cancer)



# 4.3 Clinical practices

# Impacts on clinical practices

Main ambitions of the MTS 2021-2025:

 Translation of IARC's scientific publications into clinical practices

### KPIs:

- Scientific production on clinical practices
- → ABC-DO project (case study)
- Contribution of WHO
   Classification of Tumours programme (case study)

Source: CSU, ENV, ESC

IARC contributes to clinical practice in oncology through the production of key scientific documents, as detailed below. A significant contribution is made by the WHO Classification of Tumours programme, managed by IARC. In addition, IARC's efforts in cancer survival research are noteworthy, particularly through the SURVMARK programme and the ABC-DO study, which provide critical insights into treatment outcomes and patient survival.

# Scientific production on clinical practice

IARC produces some scientific documents on clinical practice in oncology. During the current MTS, it is worth mentioning the following publications for 2021-2024:

• Patterns of Care for Women with Breast Cancer in Morocco: An Assessment of Breast Cancer Diagnosis,

Management, and Survival in Two Leading Oncology Centres, 2021

- WHO Reporting System for Lung Cytopathology, IAC-IARC-WHO Cytopathology Reporting Systems, 1st Edition, Volume 1, IAC-IARC/WHO, 2022
- WHO Reporting System for Pancreaticobiliary Cytopathology, IAC-IARC-WHO Cytopathology Reporting Systems, 1st Edition, Volume 2, IAC-IARC/WHO, 2022
- Treatment guideline concordance, initiation, and abandonment in patients with non-metastatic breast cancer from the African Breast Cancer-Disparities in Outcomes (ABC-DO) cohort in sub-Saharan Africa: a prospective cohort study, Lancet Oncology, 23(6):729-738, 2022.
- Risk of hematological malignancies from CT radiation exposure in children, adolescents and young adults, Nature Medicine, 29:3111–3119, 2023.

### WHO Classification of Tumours

Four volumes published in 2020–2021:

- Soft Tissue and Bone Tumours, WHO Classification of Tumours, 5<sup>th</sup> Edition, Volume 3 (2020)
- Female Genital Tumours, WHO Classification of Tumours, 5th Edition, Volume 4 (2020)
- Thoracic Tumours, WHO Classification of Tumours, 5th Edition, Volume 5 (2021)
- Central Nervous System Tumours, WHO Classification of Tumours, 5<sup>th</sup> Edition, Volume 6 (2021)

## Published in 2022-2023:

- Central Nervous System Tumours, 5<sup>th</sup> Edition (2022)
- Urinary and Male Genital Tumours, 5<sup>th</sup> Edition (2022)
- Paediatric Tumours, 5<sup>th</sup> Edition (2023)

### Published in 2024:

- Haematolymphoid Tumours, WHO Classification of Tumours, 5th Edition, Volume 11 (2024).
- Head and Neck Tumours, WHO Classification of Tumours, 5th Edition, Volume 9 (2024).



# WHO Blue Books Programme

Case study

# **Overview of the project**

# Objectives and target audience

# **Summary**

The WHO Blue Books programme, officially known as the WHO Classification of Tumours (WCT) series, is a cornerstone initiative led by IARC. WCT is a taxonomy of tumours including cancer, published as a series of books, commonly referred to as the "WHO Blue Books" due to their distinctive cover, and as a website. The programme is an international collaboration involving more than 2000 clinicians and scientists who synthesizes diagnostic evidence and expert consensus to produce a frameworks. The Blue Books are recognized as the international standard for cancer diagnosis and are used globally to guide clinical practice and patient management and serves as a into practice.

The primary objective of the WHO Blue Books programme is to standardize cancer classification based on pathological features including morphology and ancillary test results such as immunohistochemistry and molecular genetics. This standardized approach supports the provision of most appropriate therapy for the affected patients and the development of targeted therapies by providing detailed information on tumour type, genetic characteristics, and behaviour. The series plays a fundamental role in cancer diagnosis, treatment, and research, providing standardized and evidence-based classification to a diverse range of professionals, including pathologists, oncologists, surgeons, radiologists, molecular geneticists, cancer researchers, epidemiologists, and public health officials.

A comprehensive survey of the 5<sup>th</sup> edition, conducted in 2022, highlighted its widespread use by professionals across Asia, Europe, North America, South America, Africa, and Australia. Pathologists, including histopathologists and cytopathologists, were the primary users, but the series also serves specialists in molecular pathology, genetics, oncology, surgery, radiology, epidemiology, and nuclear medicine. Although the primary application is in clinical diagnosis of patient tumours, a significant number of respondents use the Blue Books for research and professional development.

# History and evolution of the cohort

Initiated by WHO in 1956, the Blue Books have produced five editions so far. Each Blue Books volume focuses on a specific set of tumours arising in an organ (e.g. Digestive System, Female Genital Tract, Central Nervous System) and includes detailed descriptions covering multidimensional viewpoints of a particular cancer, including histopathology, genetic characteristics, prognostic factors, and therapeutic options.

IARC has managed the Blue Books since the third edition (2000–2005), which comprehensively covered all organ sites across 10 volumes. The fifth edition significantly expanded tumour classifications, introducing two new volumes on Paediatric Tumours and Genetic Tumour Syndromes based on the specific populations affected. The sixth edition is currently in progress.

The programme's evolution is driven by the integration of new scientific insights, digital pathology, molecular research, and a commitment to supporting both HICs and LMICs. Recent editions



emphasize molecular markers and genetic mutations, which have become crucial in understanding pathogenesis, tumour behaviour, and treatment response.

The programme is also increasingly adopting digital technologies to enhance accessibility and utility. This includes the development of an online portal for easier access to content and the integration of whole slide imaging (WSI), which allows users to view high-resolution digital slides of tissue samples.

These evolutions present a significant challenge for IARC, because the Agency will need to strategically position itself in an increasingly competitive landscape. Upgrading capabilities to incorporate these advances will require substantial additional resources and funding (see VIII. Main challenges and future perspectives).

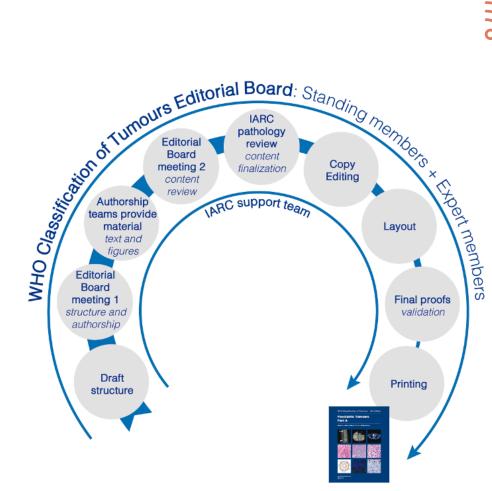
# Methodology and tools

The Blue Books programme uses a systematic and collaborative methodology to produce tumour classifications. A dedicated Editorial Board (see "Structure" section) begins by drafting an updated classification based on the previous edition but using new research evidence, which is then reviewed and refined at the first consensus meeting. This process results in a working draft that is entered into the Blue Books Online Submission System (BBOSS), a versatile database that organizes and manages content throughout the development process. Authors, selected based on recent, substantive publications and multidisciplinary expertise, are given 3–4 months to draft their sections. Their submissions are reviewed at a second editorial meeting, where content and classifications are evaluated and adjusted as necessary, with a focus on their impact on patient care and applicability in resource-limited settings. Any gaps identified during this review are addressed in the subsequent month. After in-house pathology and technical reviews, the final content is prepared for both online and print publication. The complete process typically takes 12–14 months per volume.

A key innovation of the 5<sup>th</sup> edition is the use of a relational database, enabling regular revisions to keep pace with scientific advances.

In addition to the editorial process, the histopathology laboratory plays a critical role in the Blue Books programme. This state-of-the-art facility provides essential support by providing high-quality tissue samples and whole slide images (WSI) that will be integrated into the Blue Books. This facility has been upgraded with advanced equipment like automated immunostainers and high-end slide scanners, enhancing its capacity to support both WCT projects and external research collaborations. The laboratory also serves as a resource for other IARC research teams (see "Interface with other Pillars and Branches" section).





Blue Books editorial process76

# **Structure**

### Governance framework

The Blue Books programme is managed by IARC's WCT team, which is responsible for the development and periodic updates of the series.

After the restructuring of the Molecular Pathology and Monograph sections in 2017, the Blue Books programme was established, incorporating a comprehensive editorial structure. The governance framework of the programme includes an Editorial Board comprising standing and expert members. Standing members, nominated by major pathology and diagnostic specialty organizations worldwide, represent a diverse range of expertise and geography. They serve 3-year terms, with the possibility of reappointment for an additional term to ensure continuity and knowledge transfer. Expert members are selected in consultation with standing members of the board on the basis of bibliometric searches (using the Blue Books Expert Selection Tool (BBEST), a bibliometric software that identifies potential contributors based on their recent scientific publications) and their specialized knowledge in areas relevant to each volume. They serve for the duration required to develop and publish their assigned Blue Books volume.

### International collaborative network

The Blue Books programme is at the center of three major collaborative initiatives:

→ The International Collaboration for Cancer Classification and Research (IC3R) is a global consortium initiated in 2020 and coordinated by the Blue Books programme, involving 25 institutions worldwide. It focuses on harmonizing cancer classification standards and

<sup>76</sup> Source: Blue Books programme Branch Review, 2024



integrating the latest research findings into clinical practice. By collaborating with universities, research centers, and other stakeholders, IC3R promotes universal standards for tumour classification, significantly impacting how tumours are diagnosed and studied globally.

Core members (13) include: OSEL FDA, Centre Léon Bérard, INT IRCCS - Fondazione Pascale Napoli, National Cancer Center Japan, Ospedale Pediatrico Bambino Gesu, Pathology Queensland, the Royal Brisbane and Women's Hospital, Peter MacCallum Cancer Institute, Sciensano (Federal Cancer Center of the Belgian Institute of Health), Singapore General Hospital, German Heart Center Munich, UT MD Anderson Cancer Center, The Singapore Breast Surgery Center, and IQNPath - International Quality Network for Pathology.

Full members (2) include: Association for Molecular Pathology and Heidelberg Hopp Children's Cancer Center KiTZ and Division of Molecular Neuropathology, University Hospital Heidelberg.

Associate entities (9) include: American Society of Clinical Oncology (ASCO), National Cancer Registry and Analysis Service, International Collaboration on Cancer Reporting (ICCR), Cochrane Netherlands, Laboratory of

# **Links with WHO**

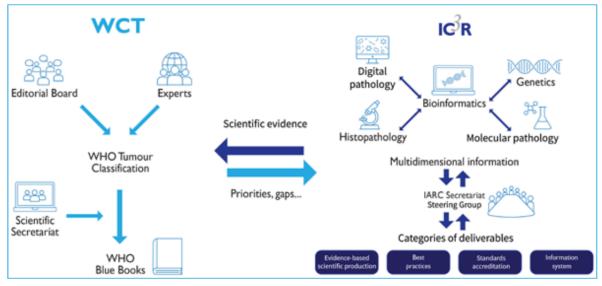
WCT collaborates closely with the WHO International Classification of Diseases (ICD) programme, which provides a standardized system for coding diseases, health conditions, and related data (see "Global reach and impact" section). Notably, WCT participates in the Medical Scientific Advisory Committee at WHO to contribute to tumour-related work in ICD-11.

In addition, WCT is strengthening ties with the NCDs team at WHO headquarters, which focuses on cancer care as part of the global NCDs strategy. This collaboration is expected to support the development of pathology services in LMICs.

WCT has also contributed to WHO's work on biological standards, advising on the production of international genomic standards.

WHO Press remains crucial to the Blue Books programme by managing the distribution of the print editions, while IARC facilitates digital access through the WCT website

Computational, Facultat de Medicina, Universitat Autonoma de Barcelona (UAB), Ulm University, Medical Faculty (Medical Faculty Division of Learning and Teaching of the Ulm University, Universidade Estadual de Campinas Sao Paolo (UNICAMP), Institute of Pathology, University Clinic of the RWTH Aachen and the University of Oxford.



IC3R model77

<sup>77</sup> Source: https://ic3r.iarc.who.int/



- → The EVI MAP project, launched in July 2022, extends these partnerships to institutions like the University of Oxford and the Maria Sklodowska-Curie National Research Institute of Oncology. The project aims to create comprehensive maps of research evidence gaps in tumour classifications through systematic review methodologies. These maps are intended to inform the Blue Books editorial process for future editions of the Blue Books and support the broader cancer research community by highlighting where additional studies are needed.
- → The Cytopathology Reporting Systems, developed through a collaboration between the International Academy of Cytology (IAC) and the Blue Books programme, are designed to standardize diagnostic practices and improve early cancer detection, especially in LMICs. These systems complement the Blue Books by providing a structured, evidence-based approach to cytopathological diagnosis. Each tumour type is described using uniform diagnostic categories, and the volume includes guidance on differential diagnosis and the application of ancillary tests such as next-generation sequencing.



Structure of the Blue Books programme<sup>78</sup>

In addition, the Blue Books programme actively engages in global coordination to advance tumour diagnosis and enhance pathology services worldwide. This involves developing Memorandums of Understanding (MOUs) with several leading international pathology organizations, including the College of American Pathologists (CAP), the Royal College of Pathologists (RCPath), the European Society of Pathology (ESP), Cancer Genomics Consortium (CGC) and the Association for Molecular Pathology (AMP). The programme works closely with various pathology colleges that accredit pathologists globally, coordinating courses and presentations based on the Blue Books, particularly in LMICs (see "Global reach and impact" section).

These efforts to harmonize tumour staging and reporting systems are further supported by collaborations with organizations such as the Union for International Cancer Control (UICC) and the American Joint Committee on Cancer (AJCC).



The programme has also developed strong links with the International Collaboration on Cancer Reporting (ICCR), making progress in dataset development.

### Resources

Funding for the production of the Blue Books is largely derived from the WCT budget, with no external funding for the books themselves. To cover costs, the books are sold at a nominal rate, with revenues shared between WHO Press and IARC. The WCT website offers digital access through subscription models tailored for both individual and institutional users, with significant discounts available for LMICs and trainees (see "Global reach and impact" section).

The programme operates with a core team at IARC, supplemented by contributions from external experts. The staff is composed of one Programme Head (RB), 4 Scientists and Support Staff (2 RB and 8 EB), and 2 Visiting Scientists.

Two core posts for production of the Blue Books, and one core post for the histopathology laboratory are funded through the Regular Budget (RB); the remainder are funded from budgets set according to income from the sales of the Blue Books.

The Blue Books programme receives additional support from public health organizations, pathology societies, and academic institutions through collaborative initiatives.

As stated in the ESC Branch Review in 2024, the indicative costs per Blue Books volume are about €527 170 (€346 699 staff costs and €180 471 non-staff costs).

# **Global reach and impact**

# Bridging HICs innovation with LMICs access

The Blue Books programme leverages advanced technology and digital platforms to ensure global accessibility and representation. With the integration of molecular and digital pathology, the programme bridges gaps between HICs, which often have access to advanced molecular techniques, and LMICs, where traditional histopathology remains more prevalent. In addition to print publications, IARC has developed an online portal (WHO Classification of Tumours Online website) that offers easy access to the Blue Books content and discounted subscriptions to LMICs and trainees, enabling pathologists worldwide to access high-quality images and reference materials.

To support the widespread adoption of the Blue Books, the WHO Classification of Tumours (WCT) team actively participates in major pathology conferences. They set up dedicated book stands to gather feedback for future improvements and to promote both print and web sales. Plans are also under way to provide WHO Blue Books to major LMICs university departments and to use the WCT website to support online case conferences and further professional development.

The Blue Books programme's collaborative efforts extend to improving pathology services and cancer diagnostics in LMICs. The Cytopathology Reporting Systems, developed in partnership with the IAC (see "Structure" section), provide standardized frameworks for cytological diagnosis, which are particularly valuable in settings with limited resources.

In addition, the Blue Books programme actively involves experts from LMICs in the development of its volumes, ensuring that the classifications are relevant to diverse health-care settings. The standing and expert editorial committees include members from LMICs, and visiting scientists



from these regions are encouraged to contribute to various WCT projects. Plans are under way to establish a WCT LMICs liaison subcommittee for the 6<sup>th</sup> edition to further strengthen this engagement. This subcommittee will focus on adapting the classifications to the needs and constraints of LMICs.

The current Head of the Blue Books programme, Dr Dilani Lokuhetty, is a specialist pathologist who served in a LMICs academic setting for 32 years.

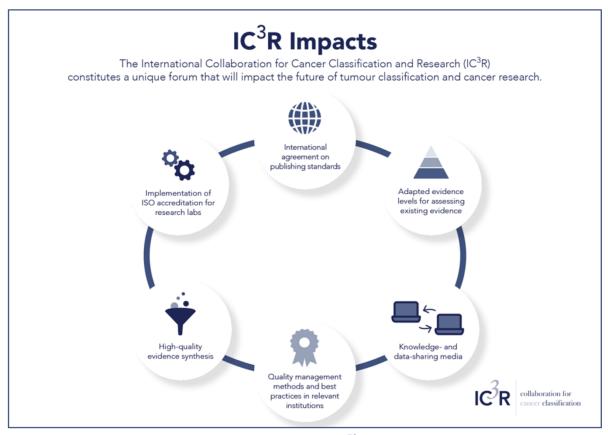
# Impact on public health policies and guidelines

The Blue Books' classifications have direct impact on individual patient care through the standards they set for diagnosis and because they provide a conduit for the implementation of research findings from IARC and from others externally.

Collaborations with international actors such as the ICCR and UICC ensure that the classifications are integrated into global cancer staging and reporting systems. These partnerships enable the harmonization of datasets like the TNM classification, a globally recognized system used to describe the extent and severity of cancer.

The classifications also guide the ICD coding systems (see "Structure" section) used in public health monitoring and policy development. A prime example of this is the ongoing upgrade from ICD-O 3.2 to ICD-O 4, which incorporates the latest tumour classifications from the 5<sup>th</sup> edition of the Blue Books.

Initiatives like IC3R (see "Structure" section) facilitate the translation of research evidence into practice, providing a platform for global coordination in cancer classification and research.



IC3R Impacts<sup>79</sup>



# **Interface with other Pillars and Branches**

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU provides global epidemiological data that informs the epidemiology sections within the WCT volumes, and the classifications are subsequently used by CSU epidemiologists.	GEM contributes molecular data for classifications. This collaboration has been particularly significant in developing new classifications, such as for neuroendocrine neoplasms, incorporated throughout the 5th edition. Insights from the Mutographs project, particularly those related to cancer etiology, are also expected to enhance the WCT volumes by informing the classification of common tumour types.  Input from the etiological epidemiology research Branches (especially GEM) at IARC helps in identifying new codes or classifications for inclusion in future editions (e.g., mesothelioma).	EGM participates in the IC3R initiative.	Strong connections in ESC between the IARC Handbooks, IARC Monographs, and WCT, with increasing coordination across their activities. This includes aligning systematic review methodologies and integrating etiological and preventive findings among the IARC Monographs, IARC Handbooks, and WCT volumes where relevant.  LCB: Training modules and online courses developed in collaboration with LCB

**Laboratory use:** Cross-Pillar contributions also include research facilities provided through the histopathology laboratory (see "Summary" section) to multiple research teams across different Pillars and Branches, such as GEM, NME, LSB, EGM, ENV, and EPR.

Cross-cutting Working Groups and Committees: Dr Ian Cree contributed as a member of the Publications Committee and chaired the Publications Software Development committee. He chaired the NC Laboratory design committee and the planning of the biobank. Dr Dilani Lokuhetty serves as member of the Laboratory Steering Committee.

Scientific integrity: Dr Dilani Lokuhetty is the Scientific Integrity Officer for IARC.



# **Key Performance Indicators (KPIs)**

The success of the Blue Books programme is measured through several quantitative KPIs, including:

- → The number of copies sold across various regions.
- → Growth in web subscriptions and traffic from individual and institutional users.
- → The number of citations in scientific literature.

# Alignment with IARC MTS 2021-2025

### Contribution to IARC's mission

Involvement in the creation and development of collaborative networks: "IARC will increasingly partner with relevant regional organizations to further advance high-quality diagnostic practice for cancer pathology and research."

→ The Blue Books programme has developed several key collaborative networks, IC3R, the EVI MAP project, and the Cytopathology Reporting Systems (see "Structure" section), which enhance the classification and reporting of tumours and cytopathological features globally.

Knowledge mobilization and capacity-building: "The WHO Classification of Tumours will continue to be available in multiple formats to meet the needs of users in low-, middle-, and high-income countries."

→ The Blue Books programme leverages digital platforms and advanced technology to provide global access to high-quality cancer classification resources, bridging the gap between HICs and LMICs (see "Global reach and impact" section). By offering training programmes, the programme enhances global capacity in cancer diagnostics and supports equitable healthcare. The creation of a WCT-LMIC liaison subcommittee for the 6th

# Level 2 objective #4, "Synthesizing and mobilizing knowledge and

The Blue Books programme supports

**Integration into the IARC Project** 

strengthening global capacities in cancer science.'

The Blue Books programme, is

under the following objectives:

integrated into the IARC Project ree

### Level 3 Objectives:

Level 2 Objective:

Tree

- Objective 4.1: "Strengthen global knowledge and global and national capacities in cancer
- research and science"
- **Objective 4.2:** "Improve the understanding and use of tumour classification to underpin cancer diagnosis, management, and research."

demonstrate a commitment to inclusivity. Impact on the development of public health policy, national or international

edition and ongoing efforts to include editorial board members from these regions

guidelines/recommendations: Positioning IARC "as a leading authority on global cancer prevention research".

> The programme also plays a crucial role in shaping public health standards through its collaboration with global organizations and integration into cancer staging and coding systems (see "Global reach and impact" section).

# Achievements of assigned objectives

Completion of the 5th edition and initiation of the 6th edition: "By 2025, the work on the 5th edition of the WHO Classification of Tumours series, which commenced in 2018, will be completed by publishing the remaining 4 out of 14 topics (volumes): Endocrine and Neuroendocrine Tumours; Skin Tumours; Eye and Orbit Tumours; and Hereditary Tumour syndromes. while awaiting the completion of the remaining 4 volumes of the 5th edition of the series, work on the 6th edition has



already commenced for 3 volumes; Digestive system tumours, Breast tumours and Female genital tract tumours".

→ The 6<sup>th</sup> edition has commenced, incorporating a more database-driven approach for integrated diagnosis and improved consistency across specialties with incorporation of new molecular genetic data.

WHO Cytopathology Reporting Systems: "In addition, IARC coordinates the generation of an associated series of publications, the WHO Cytopathology Reporting System. Already two volumes are in print: WHO reporting system for Lung cytopathology and WHO reporting system for Pancreaticobiliary cytopathology. Volumes are progressing for lymph node, soft tissue, breast, Kidney and Liver cytopathology over the next three years. This standardized terminology system will illustrate the key diagnostic cytopathological features of each particular lesion or neoplasm, discuss ancillary studies for diagnostic and prognostic evaluation, and touch on the implications of the diagnosis for patient care and management, all of which will improve the quality of diagnosis and reporting of cytopathology."

→ The Cytology Reporting Systems series (see "Structure" section) has been added to the Blue Books repertoire, which will complement the WHO Classification of Tumours while benefiting tumour diagnosis in LMIC settings. The first volumes published, on Lung Cytopathology and Pancreaticobiliary Cytopathology, have been well received, providing standardized diagnostic frameworks, particularly beneficial for LMICs.

# Main challenges and future perspectives

# Challenges

- The Blue Books programme faces financial challenges, particularly as printing costs rise and reliance on book sales persists. Although digital platforms have been introduced to provide global access at lower costs, securing consistent revenue is essential for future growth. Expanding initiatives like the Cytopathology Reporting Systems will require additional funding to support diagnostic improvements in resource-limited settings.
- The small WCT team is managing a large workload, leading to delays in book production and project completion. Staff movements due to retirements and other opportunities further impact the programme's capacity. Limited IT resources and infrastructure also pose challenges, especially as the programme integrates more digital and AI-based tools.
- Better integration is needed for tumours appearing across different organ systems because
  the quality of research evidence incorporated into the classifications is inconsistent. This
  poses challenges, especially in countries without molecular diagnostic capabilities, which may
  feel marginalized by molecular-only classifications. Collaborations like IC3R and the
  development of the EVI MAP project provide a strong foundation for advancing this area (see
  "Structure" section).
- There is a growing emphasis on incorporating AI tools into cancer classification to enhance diagnostic precision. Future challenges will include expanding research in computational pathology and ensuring that the programme stays at the forefront of emerging diagnostic technologies.



# **Perspectives**

- → IARC plans to continue expanding the Blue Books series to include the most update research evidence and emerging tumour types as genomic technologies evolve.
- → Plans include expanding the digital image library and developing AI-based diagnostic algorithms, supporting the shift towards computational pathology. Achieving these goals will require securing substantial additional funding and increasing personnel capacity.
- → The production of the 6<sup>th</sup> edition will move into full revision mode, with a target of completing three volumes per year. The ultimate goal is to complete the 6<sup>th</sup> edition by 2027. The use of WSI will be expanded, and evidence gap maps from the WCT EVI MAP project will support these updates. These tools will be integrated into future Blue Books volumes and made available to the broader research community.
- → There are plans to develop a Radiology image library with the future objective of developing a RAD-Path correlation programme and if staff and the funds permit to explore the possibility of developing a Radiology Reporting System for tumours, similar to the cytopathology series, and potentially introducing new volumes to the Blue Books series based on future needs.
- → Expanding collaborative networks for all aspects of Blue Books in LMICs is a key goal to enhance the global impact of the WHO Blue Books. Collaborative efforts with CSU will also focus on supporting local cancer registries and improving patient care through tailored classifications.
- → A key milestone will be the recruitment of a new senior pathologist by 2028 to replace the current head of the programme upon retirement.

### For more details

- → WHO Blue Books website
- → WHO Classification of Tumours online
- → IC<sup>3</sup>R website
- → WCT EVI MAP website
- → WHO Cytopathology Reporting Systems website



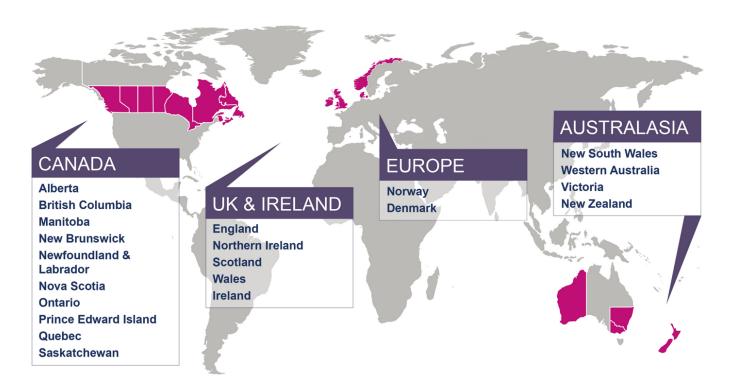
# Data and research on cancer survival

# Population-based cancer survival activities at IARC

Population-based cancer survival estimates offer crucial insights into the efficacy of cancer care services and the overall prospects for patient recovery. Through the International Cancer Survival Benchmarking project, IARC provides international projects: SURVMARK-2 and 3 (Cancer Survival in High-Income Countries), SURVCAN-3 and 4 (Cancer Survival in Countries in Transition), and SURVPOOL (A Consortium on Risk Factors and Cancer Survival). Together, these initiatives allow for comprehensive evaluations of cancer survival, incidence, and mortality in diverse health-care contexts, ranging from high-income countries to countries in transition. This benchmarking approach, rooted in multidisciplinary partnerships, aims to increase our understanding of the determinants that contribute to variations in cancer survival across different populations.

ICBP SURVMARK-2: Cancer Survival in High-Income Countries

ICBP SURVMARK-2 is an integral part of the International Cancer Benchmarking Partnership (ICBP), innovative an collaboration that unites clinicians, policymakers, researchers, and cancer data experts from high-income countries (HICs). The project aims to measure international differences in cancer survival and to identify the underlying factors contributing to these differences. Initiated in July 2016, ICBP SURVMARK-2 focuses on benchmarking cancer survival, incidence, and mortality from 21 jurisdictions across 7 HICs: Australia, Canada, Denmark, Ireland, New Zealand, Norway, and the United Kingdom. This project was completed in December 2019 and has published 17 reports on the progress in improving cancer outcomes within the partnership.



The ICBP SURVMARK-2 project includes data from 21 jurisdictions in 7 HICs.80

<sup>80</sup> Source: ICBP at Cancer Research UK.



Key objectives of the ICBP SURVMARK-2 project include:

- The provision and elucidation of up-to-date measures of cancer survival, incidence, and mortality;
- → A systematic approach to understanding how registry processes, clinical practice, and variations in stage at diagnosis impact short- and long-term survival;
- → A comprehensive assessment of progress and gaps over the period 1995–2014.

The ICBP SURVMARK-2 project uses a multidisciplinary approach to comprehensively analyse cancer survival statistics and equip stakeholders with tools for future benchmarking. The project provides survival estimates for eight key cancer types (colon, rectum, oesophagus, stomach, liver, pancreas, lung, and ovary) across the seven participating countries, which all have comparable access to health care.

ICBP SURVMARK-2 offers several outputs that drive data-driven improvements in cancer care:

- → Online database: The <a href="ICBP SURVMARK-2">ICBP SURVMARK-2</a> online database provides an accessible tool for visualizing trends in survival, incidence, and mortality over the past two decades. With survival statistics detailed by cancer stage, type, age, and country, the database enables users to explore insights that inform both immediate and long-term cancer control strategies.
- → Publications and research: Complementing the online tool, ICBP SURVMARK-2 has generated numerous studies explaining variations in survival by stage for cancers such as ovarian, colon, and rectal cancers, as well as examining the potential role of treatment differences across the countries involved. To date, 17 peer-reviewed papers highlight the marked survival differences that remain between and within countries and the specific challenges in ensuring uniform registry practice across jurisdictions.
- → Guidelines development: The research findings support the development of international guidelines for cancer staging and classification.

In 2021, IARC was commissioned to assess the impact of the COVID-19 pandemic on diagnosis and outcome among patients diagnosed with cancer within ICBP jurisdictions. Reports are being finalized for publication.

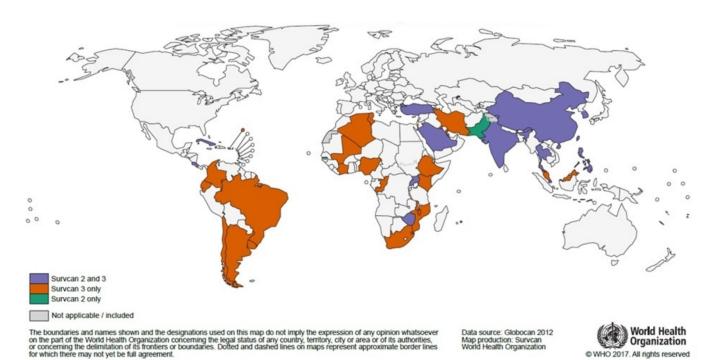
In 2024, IARC was selected for funding for the third phase of the ICBP SURVMARK research project, which will seek to leverage experience and expertise to bring cutting-edge techniques to the collection, analysis, interpretation, and dissemination of cancer-specific survival benchmarking data across ICBP countries and jurisdictions. The overarching goal of ICBP SURVMARK-3 will be to catalyse national policy changes that ultimately lead to the elimination of avoidable cancer-related deaths.

In ICBP SURVMARK-3, IARC and its collaborators will seek to understand how and why progress in improving cancer survival differs across ICBP countries. Building on the foundations of SURVMARK-2, ICBP SURVMARK-3 will add innovation through the development of novel measures of cancer survival and relevant data quality indicators. A dedicated real-world research database and benchmarking observatory (SURVMARK 3.0) will showcase these metrics tailored to each jurisdiction, to facilitate present and future benchmarking studies.

### SURVCAN-3: Cancer survival in countries in transition

The SURVCAN initiative aims to systematically provide comparative survival data from population-based cancer registries in LMICs. This effort not only facilitates comparisons between HICs and LMICs but also highlights areas of deficiency in cancer registration, clinical follow-up, and health-care planning, organization, and delivery.





Countries with invited cancer registries to SURVCAN.81

The **first volume**, titled *Cancer Survival in Developing Countries* and published in 1998, analysed cancer survival rates for cases diagnosed from 1982 to 1991. This initial study included data from 10 population-based cancer registries across five countries: China, Cuba, India, the Philippines, and Thailand.

In the **second volume**, Cancer Survival in Africa, Asia, the Caribbean and Central America, the study broadened its scope to cover cases diagnosed from 1990 to 2001 across 27 registries in 14 countries. This expanded dataset offered a more comprehensive view of survival disparities and underscored the need for targeted interventions in developing regions to improve cancer care outcomes.

Building on the success of these earlier volumes, SURVCAN-3 seeks to further enhance global understanding of cancer survival in transitioning countries. This latest instalment gathers survival estimates for multiple cancer types from more than 50 registries across Africa, Asia, the Caribbean, and South and Central America.

In addition to data collection, SURVCAN-3 emphasizes local capacity-building through partnerships with the International Association of Cancer Registries (IACR) and IARC Regional Hubs. Outputs from the SURVCAN-3 project are disseminated through several channels:

- → Online database: The <u>SURVCAN-3 online database</u> provides updated cancer survival rates across more than 30 countries and detailed by cancer type, population-based registry, Human Development Index, and Universal Health Coverage Index. The online tool enables users to explore and benchmark cancer survival statistics in transitioning settings.
- → Publications and research: Complementing the online tool, seven studies showcasing the SURVCAN-3 data and highlighting variations in survival across cancer types, geographical settings, and stage were published or are in preparation. Collaborations with local partners have also led to two published studies focusing on national experiences in terms of cancer survival in populations of different ages (Rwanda).

<sup>81</sup> Source : https://survival.iarc.fr/survcan/about/



The SURVCAN project is being pursued with a **fourth volume**, selecting high-quality population-based cancer registry data included in Cancer Incidence in Five Continents Volume XII and extending the diagnostic period to 2021, with the ambition of assessing the impact of the COVID-19 pandemic on cancer diagnosis, stage, and outcomes.

**SURVCAN-4** will continue to seek to enhance registries' expertise in collecting local data, gathering follow-up information, and performing survival analyses. To increase the global availability of cancer staging data at the population level, capacity-building activities will also be put in place to retrieve and code cancer stage for population-based cancer registries, in collaboration with the Global Initiative for Cancer Registry Development.



# **Overview of the project**

# Objectives and target audience

The primary goal of the ABC-DO study is to identify modifiable factors to reduce breast cancer mortality and morbidity in sub-Saharan Africa. The data-rich study examines multi-dimensional factors – social, cultural, economic, health system-related, and biological – along the entire care continuum that influence breast cancer outcomes.

ABC-DO was initiated because breast cancer has the potential to have a very good prognosis,

### Summary

The African Breast Cancer - Disparities in Outcomes (ABC-DO) study is a multi-country, within-African research initiative that is examining the factors influencing breast cancer outcomes for women treated in public hospitals across various sub-Saharan African settings. The study encompasses the entire breast cancer journey, from pre-diagnosis through to the post-treatment survivorship period for up to 7 years. It investigates both immediate biological factors – such as tumour biology, prognosis, and treatment – and broader socioeconomic, cultural, and health system barriers affecting early diagnosis, timely complete treatment, and survival

With more than 2300 women recruited across six countries (Ghana, Namibia, Nigeria, South Africa, Uganda, and Zambia), ABC-DO provides unique insights into region-specific challenges and informs priorities in breast cancer control. These findings are now pivotal in shaping strategies within the WHO Global Breast Cancer Initiative to reduce avoidable breast cancer deaths in similar resource-limited settings across sub-Saharan Africa.

its incidence rates are rising, primary prevention avenues are rather limited, and this cancer makes up 20–30% of all cancers in women in most African countries.

### Key objectives include:

- → To measure survival of patients with breast cancer across public hospitals in diverse African settings.
- → To identify both proximal (biological, treatment-related) and distal (socio-economic, cultural, healthcare access) determinants of survival.
- → To identify context-specific factors that can be modified to improve breast cancer outcomes.
- → To dissect the time-specified patient journey from symptom recognition to treatment completion, identifying delays that hinder an accelerated pathway to presentation, diagnosis and effective treatment.
- → To implement active follow-up using mobile technology and ensure low loss-to-follow-up rates and real-time data collection.



Because ABC-DO encompasses a broad perspective on breast cancer control and its clinical epidemiology, the target audiences for the study vary depending on the specific focus of analyses. They include health-care providers, researchers, and policymakers focused on improving breast cancer outcomes in sub-Saharan Africa. It also aims to inform international health organizations and advocacy groups working to enhance cancer care and improve survival in low-resource settings.

# History and evolution of the cohort

The ABC-DO study has grown in multiple phases. The first of these began in 2014, when competitive funding was awarded after a 2012 application to Susan G. Komen. The work was conceived in response to the global disparities in breast cancer outcomes between HICs and countries in sub-Saharan Africa, while cognizant of the fact that breast cancer incidence rates were increasing due to demographic and fertility transitions and primary prevention avenues were few. Recognizing the lack of high-quality data on survival, high losses to follow-up in previous studies, the scarcity of epidemiological and clinical data, the variations within Africa, and obstacles to improving outcomes, ABC-DO set out to fill this evidence gap, accelerating the dialogue on and actions to reduce breast cancer mortality.

In this first phase, study recruitment began in September 2014 across hospitals in four countries: Namibia and South Africa in Southern African, Nigeria in Western Africa, and Uganda in Eastern Africa. Subsequently, in 2016, a second phase of funding was awarded by Susan G. Komen directly to a fifth country, Zambia, in connection with a one-stop breast cancer clinic that was being piloted in Kabwe. By mid-2017, more than 2200 women had been enrolled in the cohort. Komen's support over the first 5 years laid the foundation for ABC-DO's success, enabling comprehensive data collection and robust follow-up. In a later, third phase supported by the US National Cancer Institute (NCI) in 2022, funding was awarded to ABC-DO Ghana, which had a similar design but shifted the focus from tertiary to secondary district hospitals so as to capture the breast cancer journey from lower levels of the health system.

Recruitment for phase I–II concluded in 2017 as the cohort had matured to more than 2200 women enrolled, and the focus shifted towards complete follow-up and comprehensive data analysis. As the study gained recognition for its potential to inform breast cancer control strategies in Africa, further funding was secured. The US NCI awarded a US\$ 1.5 million grant in 2020 for extended follow-up and analysis in the ABC-DO Plus project. This extension includes up to 7 years of follow-up, making it the first comprehensive study of its kind in Africa with this extended duration to explore critical gaps in breast cancer survival and quality of life. The extended phase will also analyze survival disparities within and between participating countries. Through scenario modelling, such as improving early detection and treatment completion rates, the study will estimate the potential survival gains under various conditions. These results will help establish realistic, actionable targets to improve breast cancer outcomes across sub-Saharan Africa.

In addition, three supplemental awards were made by the US NCI. The first supplement aimed to provide the first-ever estimates of maternal orphans due to cancer deaths in women (see III. Global reach and impact) and assess the broader impact of these deaths on families. The second supplement focuses on analysing the mutation spectrum of triple-negative breast cancer (TNBC) in ABC-DO. This work also seeks to compare TNBC mutational signatures with those found in TNBC occurring in European and North American populations, exploring links between these mutations and breast cancer risk factors such as recent pregnancies, HIV infection, and obesity. The third supplement enables initiation of ABC-DO Ghana, already mentioned above.

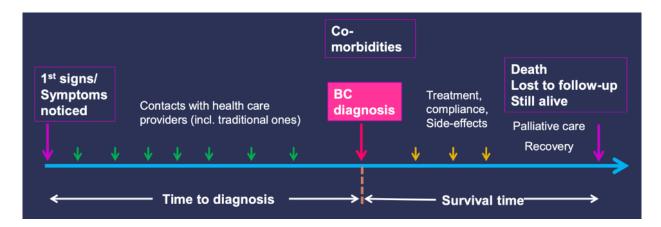


# Methodology and tools

### Study design:

ABC-DO is a longitudinal cohort study designed to track breast cancer outcomes, its consequences, and their determinants over time, capturing a wide range of factors that influence survival and survivorship. The study follows up more than 2200 women newly diagnosed with breast cancer across sub-Saharan Africa. The study aims to follow up these women for up to 7 years, with active close follow-up every 3 months thanks to an IT platform, developed with mobile health (mHealth) technologies.

The study focuses on understanding the entire patient journey, starting from the moment breast symptoms are first detected, through diagnosis and treatment, and into long-term survival and quality of life after treatment. This comprehensive approach allows ABC-DO to investigate both the biological and health-care system-related factors that contribute to disparities in breast cancer outcomes in Africa.



Timeline of the patient journey captured in the ABC-DO study82.

### Study settings:

ABC-DO is conducted in a diverse range of settings across sub-Saharan Africa to capture variations in health-care infrastructure and patient profiles. Recruitment took place in mainly public tertiary hospitals and one small private clinic in six countries:

- o South Africa: Chris Hani Baragwanath Academic Hospital Batho Pele Breast Clinic, Soweto.
- o Namibia: Windhoek Central Hospital.
- Nigeria: Maranatha Clinic and Abia State University Hospital, Aba, and Federal Medical Centre, Owerri.
- o **Uganda:** Mulago Hospital Complex, Kampala.
- o Zambia: University Teaching Hospital, Lusaka, and Kabwe General Hospital.

The original funding did not include Zambia, which was added in 2017 in the context of a one-stop breast cancer clinic being piloted in Kabwe. ABC-DO Ghana was a 2022 addition.

These settings were chosen to ensure variability in patient profiles, health-care systems, and geographical diversity. Factors such as availability of diagnostic services, treatment modalities, and support services (e.g. hospital transportation, accommodation) vary significantly across sites, allowing for a rich comparative analysis of survival outcomes in different health-care environments.

<sup>82</sup> https://abc-do.iarc.who.int/publications/presentations/





Geographical Focus of the original ABC-DO Study<sup>83</sup> ABC-DO Ghana commenced in 2022.

# mHealth study implementation:

At enrolment, women suspected of having breast cancer undergo an interview conducted by trained study nurses. This baseline interview captures a variety of social, cultural, and economic factors, along with data on access to healthcare, health knowledge, and health seeking behaviours. The study also collects clinical information, including tumour characteristics, stage at diagnosis, and any co-morbidities such as HIV infection.

The study is unique in its exploration of distal determinants of survival, such as barriers to health-care access, cultural beliefs about cancer, economic challenges, and health system limitations. These factors are assessed through structured interviews with participants, which include questions on income, education level, health-care availability, and perceptions of cancer. These data help contextualize the systemic challenges that African women face in receiving timely and effective breast cancer care. They also underline the financial toxicity of cancer treatment, with patients having no resources left to raise their children.

The study also collects detailed clinical data throughout the treatment process. In addition, data on treatment received are gathered, as well as information on treatment delays and patient compliance with treatment plans.

Active follow-up is conducted every 3 months for up to 7 years. Follow-up focuses on:

- Vital status: Monitoring whether women are alive, and if they have died, assessing the impact of the death on the family.
- Treatment adherence: Tracking whether patients are following prescribed treatments and identifying any barriers to treatment compliance. In addition, assessing whether women have access to guideline-recommended therapies.
- Health status: Monitoring patient-reported outcomes such as quality of life, treatment side effects, and overall well-being.

 $<sup>83\,</sup>https://www.iarc.who.int/wp-content/uploads/2021/03/IARC\_Evidence\_Summary\_Brief\_1.pdf$ 



o mHealth tools: A key feature of the ABC-DO study is the use of mobile health (mHealth) technology to facilitate data collection and follow-up. This approach has been crucial in ensuring low loss to follow-up and maintaining real-time data capture. The use of mobile technology helps bridge the logistic and geographical challenges commonly faced in African health-care settings and allows for frequent and efficient monitoring of patients' progress.

A unique aspect of ABC-DO is its inclusion of HIV-endemic countries in Southern Africa. Up to 25% of younger patients with breast cancer in these countries are women living with HIV (WLHIV). At the start of ABC-DO, there was limited information on how WLHIV who develop breast cancer compared with HIV-free patients with breast cancer in terms of breast cancer biology, survival, treatment toxicities, and adherence.

An innovative aspect of ABC-DO Plus is its exploration of molecular epidemiology, including PAM50 gene expression profiling and other molecular analyses, to deepen the understanding of breast cancer biology in women of African ancestry.

# **Structure**

### Governance framework

The governance framework of the ABC-DO study is led by a team of principal investigators from IARC and the London School of Hygiene and Tropical Medicine, supported by experienced epidemiologists based at IARC.

The study also benefits from expert advisory support from specialists from the WHO's Global Breast Cancer Initiative (GBCI) (see below).

Expertise beyond these core teams is sought for various specific investigations. For example, ABC-DO has invited collaborators with expertise in geographic information systems, molecular epidemiology, immune tumour biology, health-systems research, patient advocacy, and, in the context of the work on maternal orphans, in health inequities, male fertility, demographics, and child development.





### International collaborative network

The ABC-DO study operates through a robust international collaborative network, which includes key institutions and hospitals across sub-Saharan Africa, North America, and Europe. Collaborators include leading hospitals and universities in South Africa, Namibia, Nigeria, Uganda, Zambia, Ghana, and Germany, with prominent partners such as Chris Hani Baragwanath Academic Hospital in Soweto, South Africa, and Makerere University in Kampala, Uganda. The study has strong ties with institutions such as Halle University in Germany.

### Resources

The ABC-DO study initially received funding from Susan G. Komen, which provided support for the first 4 years.

After this, the US National Cancer Institute (NCI) awarded a grant (R01 CA244559) to continue the work, alongside smaller funding supplements.

# **Links with WHO**

The ABC-DO study preceded GBCI, and thus informed its development, and unsurprisingly it now aligns closely with the GBCI led by WHO headquarters. One of the study's early contributors was a key figure from WHO headquarters, who has been part of the ABC-DO project from the outset and serves on both the GBCI and ABC-DO executive/advisory committees. The knowledge gained from ABC-DO has directly contributed to shaping the GBCI (see III. Global reach and impact).

The ABC-DO PIs are shaping the GBCI's Technical Documents, including the WHO 2025 Global Status Report on Cancer and the WHO African Region's Breast Cancer Technical Document, which is in the making during 2024–2025 as a region-specific response to the WHO GBCI.

The study has successfully raised US\$ 1 million from Komen and US\$ 1.5 million from the US NCI, including additional funds in the form of supplement grants to support the maternal orphans research project and genome-wide sequencing of triple-negative tumours (US\$ 329 000), and a mentoring grant to initiate ABC-DO Ghana. Overall, approximately half of the funds are allocated directly to African countries for research conduct.

Over the past decade, ABC-DO funds have supported salaries for a dedicated team at IARC, including three IARC staff scientists, four postdoctoral researchers, and three PhD students.

The project also benefits from a team of experts based in each country. Several photographsof the teams of PIs and study interviewers involved in ABC-DO are shown here.



ABC-DO study meeting, Uganda, 2022



# **Global reach and impact**

# Bridging HICs innovation with LMICs access

Breast cancer is the most common cancer type in women in sub-Saharan Africa, with 129 000 women newly diagnosed in 2020 alone. However, breast cancer survival in the region is alarmingly low compared with HICs. Whereas 5-year survival in the USA reaches 80% for Black women and 90% for White women, survival levels in sub-Saharan Africa are often near or below 50%, meaning that half of the women diagnosed with breast cancer die within 5 years. The annual number of breast cancer diagnoses is projected to nearly double by 2040 due to population growth and ageing, and this increase could be even more significant if lifestyle and reproductive changes (such as fewer children and later childbirth) are factored in. The ABC-DO study was specifically designed to understand these disparities by examining determinants of breast cancer survival across sub-Saharan African countries. ABC-DO is the largest and most comprehensive study of breast cancer outcomes in these regions (see I. Overview, 3 Methodology and tools).

# Key findings:

- Survival and how to improve it:
  - Breast cancer survival is alarmingly low in black African women. At 3 years, survival in ABC-DO was 90% in White Namibian women, 58% in Namibian and South African Black women, 46% in Ugandan and Zambian women, and 36% in Nigerian women.
  - Late stage at diagnosis and lack of access to surgery and systemic therapy, which
    particularly affected women from lower socioeconomic groups, were the largest
    contributors to low survival. The relatively high proportions of young-onset breast cancer
    (< 30 years at diagnosis), HIV-positive women, and more-aggressive tumour subtypes made
    only a small contribution to low overall survival. Still, among patients with breast cancer who
    were also living with HIV, their mortality rates were 30-40% higher than among their HIVnegative counterparts.</li>
  - The study's mHealth trimonthly contacts with women proved successful. Mobile phones
    can be used to keep in contact with women for years after diagnosis, and they may form a
    critical element of interventions to support women through their breast cancer journey.
- → Advanced breast cancer and the journey to diagnosis:
  - The major contributor to advanced disease at diagnosis is the extensive time period with symptoms, with median times of 7 months (Black Namibian women), 8 months (Zambian women), and 11 months (Ugandan women) between symptom recognition and final diagnosis. Faster-growing tumours (e.g. triple-negatives) are associated with more advanced disease but are not the primary drivers of late stage.
  - The period from a woman's symptom recognition to contacting a health-care provider tends to be shorter than the period between the first contact with a care provider and diagnosis. During this time, patients see a small number of providers, but the time between provider visits is excessively long (> 3 months).
  - Women who know that breast cancer can be cured are diagnosed earlier.
  - Breast cancer awareness levels are low; 2 in 3 women in Uganda do not know that the
    disease is curable. Myths about its causes (e.g. curses, money or phones in the bra) are
    prevalent.
  - Geospatial barriers to an earlier diagnosis have been quantified, highlighting later stage in rural populations.

### Therapeutic gaps:

 14% of ABC-DO women with non-metastatic disease did not receive any treatment within the first year of diagnosis. Women from lower social groups are at greatest risk of not



receiving treatment, highlighting the need for financial, educational, and emotional support to increase treatment access and treatment completion proportions.

- → Wider societal impact: maternal orphans:
  - ABC-DO has unveiled wider intergenerational impacts of cancer deaths in Africa. Half of breast cancer deaths occurred before age 50 years and, on average, for each one of these deaths 2 maternal orphans were left behind. The catastrophic financial expenditure of the cancer treatment has impacts on families' concerns for children's future care and education. In addition, through its supplement study (see I. Overview of the project, 2. History and evolution), ABC-DO extended this work globally, revealing that more than 1 million children were orphaned by maternal cancer deaths in 2020, half of which were due to breast, cervical, and upper gastrointestinal cancers. These findings are a powerful impetus for action and were recognized by WHO Director-General Dr Tedros Ghebreyesus on World Cancer Day 2023.

# Impact on public health policies and guidelines

The ABC-DO study has made significant contributions to shaping public health policies related to breast cancer in sub-Saharan Africa. Key findings from the study have been disseminated to stakeholders, including WHO, ministries of health, and patient groups. Where the ABC-DO recruitment sample represents a substantial patient profile in an individual country, country-specific focus articles have also been produced, the first being for Namibia. This country focus provides a user-friendly snapshot for ministries of health in individual countries.

The IARC Evidence Summary Brief on ABC-DO findings published in March 2021 is a key contribution to the dissemination of these results, including a call to action for better awareness, rapid diagnostic, and access to treatment.

# Call to action



Improve breast cancer awareness among women, communities, and health professionals.



Support rapid (< 2 months) diagnostic investigations of suspected breast cancers.



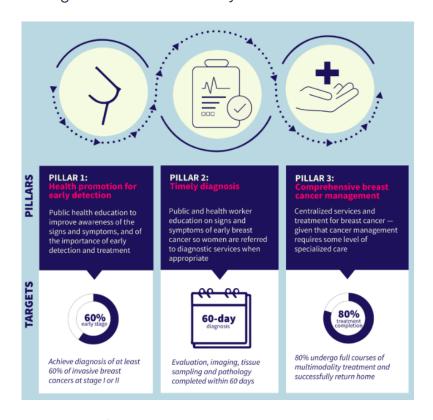
Improve access to systemic therapy and surgery, and support completion of treatment courses.

Breast Cancer Outcomes in Sub-Saharan Africa.84

The study has directly influenced the WHO Global Breast Cancer Initiative (GBCI), helping define key performance indicators for breast cancer control across its three pillars. WHO has used the study's insights to guide breast cancer control strategies, particularly in sub-Saharan Africa. For example, ABC-DO has played a role in shaping the WHO African Region's breast cancer control guidelines.



The work of the ABC-DO study has also been featured in high-level forums such as the AORTIC conferences (2017, 2019, 2021, and 2023) and the World Cancer Congress, further disseminating its findings to the broader global health community.



The three pillars of the WHO Global Breast Cancer Initiative (GBCI).85

# **Interface with other Pillars and Branches**

Pillar 1	Pillar 2	Pillar 3	Pillar 4
CSU: The ABC-DO findings of the extent of maternal orphans led to an ENV-CSU collaboration on the first-ever global estimates of maternal orphans due to cancer, published in Nature Medicine in 2022 (Guida et al.), while the analogous estimates for paternal orphans are in the making. These will all be publicly available on the Global Cancer Observatory website in due course.	GEM: From its outset, ABC-DO has had excellent collaboration with GEM through pathology support by Dr Behnoush Abedi-Ardekani, who provided in-person pathology training to the ABC-DO pathologists.  NME and EGM: Mutation patterns of triple-negative breast cancer are being analysed in collaboration with NME and EGM. Furthermore, in 2025–2026 ABC-DO South Africa data will be used by an NME young scientist who has received a WCRF INSPIRE award.		

<sup>85</sup> https://www.who.int/initiatives/global-breast-cancer-initiative



# **Key Performance Indicators (KPIs)**

KPIs used for the ABC-DO study include:

- → Participant recruitment (see I. Overview of the project): Number of women recruited, monthly per country;
- **Participant retainment**: Loss to follow-up rate:
- → Data completeness: Ensuring complete data across the breast cancer journey, including critically for treatment data and its dynamic nature;
- → Fieldworker retainment: Low losses to follow up can be aided by low study staff turnover, thus staff (interviewer) turnover was monitored;
- → Capacity building: Number of PhD students supported; Training courses
- → Impact on Public Health policies (see III. Global reach and impact).
- → Dissemination and awareness: Number of peer-reviewed publications; Presentations at global conferences

# **Alignment with IARC MTS 2021-2025**

# Contribution to IARC's mission

Involvement in the creation and development of collaborative networks: "IARC will increasingly partner with relevant regional organizations to further advance high-quality diagnostic practice for cancer pathology and research."

→ The ABC-DO study successfully established collaborations with institutions across sub-Saharan Africa. It involves a multidisciplinary network of hospitals, universities, and cancer associations in five African countries, promoting partnerships that enhance diagnostic practices and research capacity (see II. Structure, 3. International collaborative network).

Knowledge mobilization and capacity-building: "IARC is well placed to develop appropriate and tailored capacity-building programmes and to identify the most relevant target audiences for training or mentoring activities."

→ ABC-DO supports the training and capacity building of seven cancer researchers from various institutions across Europe and Africa. Capacity-building initiatives include training of pathology specialists, supported by Susan G. Komen.

# Achievements of assigned objectives

Support to improving survival of women with

breast cancer in LMICs: "Research to improve survival of common curable cancers in LMICs will focus on the epidemiology of breast cancer in

# Integration into the IARC Project Tree

The ABC-DO study is integrated into the IARC Project Tree under the following objectives:

- · Level 2 Objective: The ABC-DO study supports Level 2 Objective #3, "Evaluating cancer prevention interventions."
- · Level 3 Objectives:

Objective 3.1: "Enhance understanding of evidence-based interventions for cancer prevention and control to support their practical application, including those related to cancer disparities."

Objective 3.2: "Enhance understanding of the efficacy and effectiveness of populationbased interventions and cancer prevention programmes."

Objective 3.3: "Enhance understanding about the development and application of biomarkers for early detection and outcomes through translational studies."

In addition, the study supports the **Emerging** priorities 2 and 3: "Implementation research" by providing the formative data needed before to the identification of interventions, as well as "Economic and societal impact of cancer" as evidenced by the world's first study to highlight the intergenerational impacts of cancer.

presentation/diagnosis, treatment, and ultimately survival."

sub-Saharan Africa, including studies of barriers, within a social and cultural context, to early



→ As illustrated in the ABC-DO output to date, this data-rich cohort has demonstrated the quality and scale of epidemiological studies that can be conducted in sub-Saharan Africa, notably of cohorts of patients with cancer. The study model was mimicked in a South Africa-wide analogous study. In addition, in March 2021, ABC-DO became the focus of IARC's first-ever Evidence Summary Brief, designed to effectively communicate the study's key findings to a wider audience. This initiative ensures that ABC-DO's critical insights are accessible to policy-makers, health-care professionals, and stakeholders involved in cancer control, amplifying its impact on public health efforts.

# Main challenges and future perspectives

- Translating evidence into actionable policy: The ABC-DO study has made significant strides
  in identifying the priorities for breast cancer control in sub-Saharan Africa. This formative work
  will be carried forward, to identify interventions and health systems strengthening to translate
  these findings into interventions, implementation, and actionable policies. ABC-DO is often
  involved in discussions with policy-makers and health authorities about the plans to strengthen
  cancer care.
- Focus on long-term survival and quality of life: Planned future activities will focus on long-term survival trends, quality of life during and after treatment, and understanding barriers to treatment completion. In addition, the ABC-DO study will continue contributing to global breast cancer research and policy, particularly in collaboration with the WHO GBCI.
- ABC-DO continues to provide insights into the **problem of breast cancer in sub-Saharan Africa**. Over the next few years, some of the many questions the study hopes to answer are:
  - o How does HIV infection affect quality of life and treatment completion?
  - How does quality of life vary over time, overall, among survivors and among women during the terminal phase of life?
  - Why do young women with breast cancer (< 40 years at diagnosis) have lower survival?</p>
  - What are the breast cancer control priorities for older patients with breast cancer in this setting?
- Molecular profiles of breast cancer tumours: The ABC-DO study also plans to continue genotype analysis to further understand the molecular profiles of breast cancer in African women. There is a project to conduct genome-wide sequencing on triple-negative breast tumours and compare results with similar data from France.
- Expanding to other cancer types: The potential to expand the ABC-DO model to other
  cancers, such as childhood cancers, is also being explored. Moreover, there are plans to
  integrate breast cancer and cervical cancer into a unified women's health approach, offering
  educational and diagnostic support across both cancer types. HIV-positive patients with
  breast cancer remain a key focus, with ongoing efforts to establish treatment guidelines for
  this high-risk population.
- Actions to improve breast cancer control: IARC is engaged in several research studies that were initially informed by the formative work in ABC-DO. These include: (i) the MyCare study in the United Republic of Tanzania, Ghana, and Kenya to assess whether breast health awareness

messaging can be disseminated in Africa via menstrual hygiene products (ENV-led); (ii) the ABC-DE study in Uganda to test whether a hand-held ultrasound device can improve the accuracy of CBE referrals (EPR-led); (iii) a feasibility study of CBE training of first-line health-care workers in Ghana (ENV-led); and (iv) evaluation of a new walk-in breast cancer clinic in Namibia and of a supported referral system from the community to treatment hospitals in Zambia (ENV-led).

#### For more details

- → ABC-DO study website
- JARC Evidence-Summary Brief on ABC-DO findings
- → WHO Global Breast Cancer Initiative website



# 4.4 Economic and societal impacts

### **Economic and societal impacts**

Main ambitions of the MTS 2021-2025:

 Integration of economic and societal impacts into IARC programmes and studies

#### KPIs:

- → Health economics and cancer
- Research Team: Cancer inequalities (case study)

Source: CSU, other Branches

IARC's scientific production on economic and societal impacts of cancer focuses on Health Economics and Cancer Inequalities. Those topics are part of the MTS emerging priorities. A dedicated Research Team was planned for each of these two topics: the Health Economics and Cancer Team (HEC) and the Cancer Inequalities Team (CIN). The activities of the CIN Team are described below. The HEC Team did not materialize during the current MTS period, so a short summary of IARC's work in health economics is presented.

### Health economics and cancer

Currently, there is no formal Research Team at IARC solely responsible for health economics, due to some difficulties of the Agency to recruit the appropriate

expert. Therefore, the work in this area is being handled by individuals within the CSU Branch, including a PhD student, a P3-level staff member, and a postdoctoral scientist who joined in September 2024. A health economist position has been advertised, and more than 100 applications have been received by the Agency, with the goal to have a candidate in place by January 2025.

In that context, IARC's current work in health economics focuses on the following topics:

- Economic cost of cancer: The first aspect of the work on health economics and cancer focuses on the economic cost analysis. A PhD student, supported by health economists from the Scientific Council, has been continuing the analytical work on the economic burden of cancer, initially developed by a previous researcher. This analysis calculates lost income to society due to cancer-related deaths and is now expanding to include unpaid labour, particularly in LMICs. The work is conducted at the country level, using employment and salary data sourced from the International Labour Organization (ILO) and national statistics. The analysis has completed the estimation of the economic cost of cancer-related deaths and is now shifting to estimating the costs associated with absenteeism and sick leave, particularly for common cancer types such as breast cancer, as well as cancers affecting younger populations.
- Informal care costs: The second focus is on the informal care provided by family members and its indirect costs. The recruited economist will take over the medical cost calculation; the current work focuses on the non-medical side of these costs.
- Women and cancer: Another ongoing project, inspired by the Lancet Commission on Women, Power, and Cancer, explores the impact of cancer on women, particularly focusing on out-ofpocket expenditures in LMICs. This work will become more comprehensive with the recruitment of a health economist.
- Cervical cancer elimination economics: A final project involves calculating the benefits of
  cervical cancer elimination, in collaboration with WHO. This work uses data from the Elimination
  Partnership in the Indo-Pacific for Cervical Cancer (EPICC) and applies an average model from
  WHO, which is based on models developed by Harvard University, the University of Toronto,
  and the University of Sydney. The analysis provides estimates for the timeline of cervical cancer



elimination and incorporates return on investment (RoI) calculations for 78 countries, primarily LMICs in line with WHO's initial focus. However, the model could be extended to high-income countries (HICs) in the future. Plans also include integrating productivity losses into the model. Pilot countries such as Nigeria are already using the tool to plan their national cancer plan, although it is not yet publicly available.

As next steps, the CSU Branch plans to address the following challenges:

- → CSU aims to continue these projects with the goal of developing a comprehensive cancer economics database that will encompass direct costs, productivity losses, informal care costs, and other related factors. The goal is to provide a complete overview of cancer-related economic costs by 2030, creating a tool that will be unique on a global scale. This database will be fully integrated into the Global Cancer Observatory.
- → CSU is exploring the possibility of expanding its work on the economics of cervical cancer elimination to include other cancers, particularly those aligned with IARC's three initiatives: cervical, breast, and childhood cancer. Breast cancer has been identified as a potential next target, although the role of prevention in breast cancer is relatively limited compared with cervical cancer.
- This tool will help countries, especially in LMICs but also, if the project develops as planned, in HICs, in the planning phase of the national cancer plan.
- → WHO regional offices may be interested in supporting cervical cancer tools in regions such as Eastern Europe.
- → There are ongoing internal discussions about the synergies between IARC's current health economics work and related projects, particularly those being developed by the EPR Branch, including the PHDS Team working on cervical cancer modelling in the EPR Branch using a different model from those of the CSU Branch.
- → Securing grants for these projects can be challenging, because countries often view descriptive health economics as routine work. However, as demonstrated by recent direct funding from Nordic countries for a related prevention programme, future funding is more likely to come from direct partnerships rather than competitive grants, once the project's effectiveness has been demonstrated.

# **Cancer Inequalities (CIN) Team**

### **Members**

**Team leader:** Dr Salvatore Vaccarella (Scientist, CSU)

Team members: The CIN Team consists of 10 members from the CSU Branch as mentioned below, as well as collaborators in others Branches: Dr Valerie McCormack (ENV), Dr Heinz Freisling (NME), Dr Pietro Ferrari (NME), Dr Komodo Matta (NME), and Mr Damien Georges (EPR).

→ Dr Marzieh Eslahi (Postdoctoral Scientist, CSU);
Dr Maxime Large (Postdoctoral Scientist, CSU);
Dr Margherita Pizzato (Visiting Scientist, CSU);
Dr Sébastien Lamy (Visiting Scientist, CSU;
INSERM, Toulouse, France); Dr Valentina
Lorenzoni (Visiting Scientist, CSU; Sant'Anna
University, Pisa); Mr Mohamed Youcef Ali
(Master's Student, CSU); Dr Freddie Bray
(Branch Head, CSU); Dr Hadrien Charvat
(Visiting Scientist, Scientific Consultant, CSU);
Dr Olga Trusova (Visiting Scientist, CSU); Dr
Serra Kerman (postdoctoral scientist/project
manager)



# **Objectives**

The CIN Team has four main objectives:

# 1. Addressing socioeconomic inequalities in health

The need to reduce socioeconomic inequalities in health and cancer is increasingly recognized as a matter of social justice and human rights. acknowledged as beneficial economic perspective, making it a priority in public health agendas and the Sustainable Development Goals.

# 2. Understanding social inequalities in cancer

Social inequalities in cancer remain a critical public health issue, affecting all individuals but disproportionately affecting the most disadvantaged groups. These inequalities have significant financial repercussions for societies and profoundly influence health outcomes. Understanding how these inequalities evolve over time necessitates a comprehensive perspective that considers economic, social, political, legislative, and technological forces. These factors shape the distribution of risk factors within populations and influence access to health-care services, which contributes to the observed disparities in cancer outcomes. Moreover, psychosocial factors often lead individuals of lower socioeconomic status to adopt unhealthy behaviours, exposing them to a greater variety and intensity of cancer risk factors compared with their more advantaged counterparts. To monitor, investigate, and address these issues effectively, high-quality data on populations are essential, requiring multisectoral action to develop effective solutions to social inequalities in cancer. Research plays a vital role in providing the necessary data to inform evidence-based interventions aimed at reducing these inequalities (IARC Scientific Publication No. 168).

#### 3. Measuring and monitoring inequalities in cancer

The CIN Team aims to measure and monitor social inequalities in cancer incidence, survival, and mortality, recognizing that these disparities vary across different populations. The social gradient in cancer reflects complex patterns both between and within countries, driven by a multifaceted interplay of factors. The Team's objectives include comparing these inequalities across populations within the broader context of the global epidemiological transition of cancer, while also addressing inefficiencies in healthcare provision, such as overdiagnosis.

### 4. Clarifying mechanisms behind inequalities

The CIN Team is committed to elucidating the mechanisms – particularly the structural determinants of health – behind social inequalities in cancer. This includes examining factors at all levels (individual and contextual, proximal and distal) and along the entire cancer continuum, from risk factors and prevention to early detection and treatment.



# Cancer Inequalities Team - the vision Human development & cancer transitions Underuse of healthcare Socioeconomic inequalities Overuse of healthcare Overdiagnosis/overtreatment Cancer Cancer Cancer Availability of healthcare Socioeconomic condition Socioeconomic condition

# Workplan progress

### Projects and consortia

The members of the CIN Team are actively engaged in eight scientific consortia, with IARC acting as Principal Investigator (PI) in three of them: EUCanIneq, Socineq, and Thycost. The CIN Team emphasizes its involvement in European projects, including:

- EUCanIneq (PI)
- UNCAN.eu (Task Leader)
- EUCervScreen (Work Package Leader)

### Applications and grants

Since 2021, the CIN Team has successfully contributed to nine grant applications, securing a total of €1.328 million in funding for IARC. The details of the projects are as follows:

#### Governance

The leader of the CIN Team indicated that regular discussions take place with Team members, whether in person or via teleconference. These meetings also include visiting scientists who are based outside of IARC.

### Collaboration with WHO

The CIN Research Team has collaborated with the WHO Regional Office for Europe on the publication titled "Childhood Cancer Inequalities in the WHO European Region." In addition, Team members have analysed incidence rates across countries as part of the WHO Cervical Cancer Elimination Initiative.

Project	Role	Period	Grant Amount
EUCanIneq	PI	Feb 2023 to May 2025	€600,000
UNCAN.eu	Task Leader	Sept 2022 to Nov 2023	€54,000
EUCervScreen	WP Leader	Sept 2023 to Aug 2026	€21,000
Cancerfonden	PI	Until February 2024	€120,000
Socineq/INCa	PI	Until November 2027	€263,000
Meta-thyr/INCa		Until March 2027	€60,000
Silica		Ended May 2023	€42,000
SISCanS			€40,000
Thycost/INCa	PI		€128,000

### **Publications**

Since 2020, the CIN Team has produced 44 articles (including two currently under revision), with 22 authored as first, last, or corresponding authors. Of these publications, 29 specifically address social inequalities in cancer. The Team's work has appeared in several high-impact journals (see "Key publications" below).



### **Key collaborations**

Cooperation across IARC Branches
The CIN Team primarily relies on
scientists from the CSU Branch but
maintains close collaborations with other
Branches, particularly with NME in Pillar 2
and EPR and ENV in Pillar 3.

Collaboration with external partners
The CIN Team has a broad network of
scientific partners, which includes
prominent institutions such as Erasmus
MC in the Netherlands and Imperial
College London and UCL in the United
Kingdom, among others.

### **Training**

Training is a crucial component of the CIN Team's activities. The Team Leader ensures that members participate in various training opportunities, including:

- External courses:
- "Introduction to Multiple Imputation for Missing Data" (Victorian Centre for Biostatistics)
- CLADAG School on Statistical Methods for Unsupervised and Supervised Learning (Italian Statistical Society)
- Courses on Medical Statistics (University of Milan)
- Systematic Reviews and Meta-Analyses (University of Milan)
- Economic Evaluation of Public Health Interventions (EUPHA Public Health Economics Section)

- Internal courses:
  - o "Statistical Practice in Epidemiology using R"
  - IARC Summer School
  - o Training on Childhood Cancer Registration

Routine internal training is also conducted informally on topics relevant to descriptive cancer epidemiology, such as age-period-cohort models and survival analysis techniques.

#### Invited talks and events

Members of the CIN Research Team have contributed to various invited talks and events, including:

- Cancer Prevention Research Conference (June 2024, CRUK, NCI, ACS, Boston, USA) –
   Chairing the session on health inequities in cancer incidence and prevention
- o Thyroid Cancer Conference (November 2023, Verona, Italy)
- o Breast Cancer Conference (October 2023, Montpellier, France)
- Guangdong Outstanding Overseas Teacher Program (October 2023, China)
- ECO High-Level Meeting (June 2023, Brussels, Belgium)
- o IPV Conference (April 2023, Washington DC, USA)
- o Columbia University (April 2023, New York City, USA)
- o Imperial College London (March 2023, virtual)
- World Cancer Conference (October 2022, Geneva, Switzerland)
- o American Thyroid Association (October 2021, virtual)

### **Main innovations**



The CIN Team addresses the paradox within healthcare systems, focusing on both the underutilization of healthcare services and preventive measures by individuals with low socioeconomic status and the overuse of low-value care among those with greater access to health services. This dual focus highlights the need for equitable healthcare practices. In collaboration with ENV, the CIN Team studies the

consequences of maternal orphanhood due to cancer, revealing a cycle of disadvantage and poverty. The CIN Team has contributed to various policy reports on cancer, including recommendations on the overdiagnosis of thyroid cancer, which have led to significant changes in guidelines and clinical practices informed by IARC's research.

At the European level, the CIN Team has played a pivotal role in several key initiatives, such as:

- The European Cancer Inequalities Registry
- The UNCAN.eu project, particularly Work Package 6 on Inequalities in Cancer Research
- The WHO Regional Office for Europe report on "Childhood Cancer Inequalities in the WHO European Region"



# **Contributions to MTS implementation**

### Fundamental priorities

→ The research on cancer inequalities is a significant topic under the first fundamental priority of IARC's MTS: "Data for Action". It aims to enhance understanding of the causal pathways linking social disadvantage to health disparities and to support countries in collecting data to better describe cancer disparities globally. The CIN Team's work contributes directly to this initiative and should foster stronger collaborations with other scientific Branches, particularly those focused on nutrition and environmental influences on cancer.

### **Emerging priorities**

→ Cancer inequalities are a critical component of the third emerging priority of the MTS 2021-2025, focusing on the "Economic and Societal Impacts of Cancer." The MTS states that "the cancer burden is not equally distributed across countries, within countries, and between different groups within societies." Structural determinants of health, including social and economic conditions, produce significant social gradients in cancer incidence, survival, and mortality. IARC is well-positioned to address these issues through its capability to catalyse research partnerships and analyse international studies.

# Main challenges

The CIN Team aims to elevate cancer inequalities from an "emerging priority" in the MTS 2021–2025 to a fundamental priority in future iterations of the strategy. To achieve this, the Team must define strategies to enhance IARC's leadership and impact in this domain, including strengthened fundraising efforts and collaboration with key partners such as the OECD. Key points emphasized by the Team leader include:

- The CIN Team is already recognized as a leader in the fields of social inequalities in cancer and overdiagnosis, as evidenced by numerous high-impact publications and invitations to major conferences. These topics are likely to gain further importance in the global agenda and at IARC; however, sustaining or expanding this high-level focus is challenging with reliance on temporary staff funded by grants.
- Having even a part-time, fixed-term data manager/statistician could ensure continuity in the CIN Team's activities over time.
- Although the CIN Team has successfully secured project-specific funding, long-term support is necessary to maintain its position and facilitate growth.

# **Next steps**

The CIN Team leader plans to develop scientific projects focused on:

- → The field of cancer inequalities.
- → The issue of overdiagnosis in cancer.



### **RECOMMENDATIONS**



- ✓ The CIN Team should strengthen cross-cutting collaborations within IARC and integrate members from outside the CSU Branch.
- ✓ The Team leader should consider establishing a co-leadership structure with scientists specializing in implementation research from the EPR Branch to enhance the effectiveness of the Team's efforts.

# **Key publications**

- Malagón T, Franco EL, Tejada R, Vaccarella S. <u>Epidemiology of HPV-associated cancers past</u>, present and future: towards prevention and elimination. Nat Rev Clin Oncol. 2024
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- Lortet-Tieulent J, Georges D, Bray F, Vaccarella S (2020). <u>Profiling global cancer incidence</u> and mortality by socioeconomic development. Int J Cancer. 147(11):3029–36. PMID:32449164

### References

- Web page of the Research Team
- IARC Scientific Publication No. 168: Reducing Social Inequalities in Cancer: Evidence and Priorities for Research
- World Cancer Report Webinar Series, Social inequalities and cancer



# Main conclusions and recommendations: impacts



### **Cooperation with WHO**

The collaboration between IARC and WHO headquarters has been formalized through a joint strategic workplan for 2023–2025, which includes shared governance and partnerships on the three global cancer initiatives (on childhood, breast, and cervical cancers). Governance mechanisms for the *IARC Monographs* and *IARC Handbooks* programmes are outlined in a Standard Operating Procedure (SOP), which is currently under revision. In addition, IARC collaborates with WHO headquarters and IAEA in the formulation of national cancer control programmes (NCCPs). The three IARC Research Teams dedicated to the global cancer initiatives have made a significant contribution to effective coordination with WHO and the translation of research into public health policies.

Moving forward, the next joint strategic workplan should incorporate collaborations with WHO regional offices, enabling IARC to further promote cancer prevention measures at the local level.

### **Prevention policies**

Several IARC programmes play a direct role in shaping public health prevention policies alongside WHO. However, they face specific challenges:

- → The IARC Monographs and IARC Handbooks programmes require better alignment with WHO headquarters through the revised SOP to ensure that their findings are effectively translated into public health recommendations. In addition, the IARC Monographs programme is currently too reliant on a single funder, posing risks to its independence and sustainability.
- → The Codes Against Cancer must accelerate their dissemination and expand through regional adaptations in Asia, Africa, and the Middle East.
- → Meanwhile, CanScreen5 should strengthen its global database on secondary prevention and prepare for integration with the Global Cancer Observatory (GCO), enabling IARC to offer a unified online portal for cancer data.

### **Clinical practices**

Although not directly focused on primary or secondary prevention, IARC contributes to oncology clinical practices through key scientific resources.

→ The WHO Blue Books should complete their transition to a digital platform, offering online access to the WHO Classification of Tumours and preparing for advances in computational pathology and AI.

IARC's cancer survival programmes (SURVMARK, SURVCAN, SURVPOOL, ABC-DO) provide crucial insights into treatment completion and quality of life during and after cancer treatment.

→ These programmes should explore new areas of research, including tertiary prevention and the factors influencing disparities in cancer survival across different populations and countries.



### **Economic and societal impacts**

IARC has conducted valuable studies during the MTS period to measure and address social inequalities in cancer incidence, survival, and mortality, demonstrating disparities across populations. Understanding the social determinants of health and inequalities is vital for managing risk factors throughout the cancer continuum.

→ Although IARC has made significant progress at the European level, the Agency should expand this research globally to further contribute to reducing health inequalities in cancer prevention.

During the same period, IARC produced insightful studies on the economic cost of cancer, including informal care costs and models for prevention measures, such as cervical cancer elimination.

- → However, the Agency has yet to establish a dedicated Research Team on health economics, a goal it should continue to pursue.
- → IARC should also maintain its ambition to enhance the Global Cancer Observatory with new features on health economics and social inequalities, creating a comprehensive platform for cancer surveillance and prevention data.

# IARC MTS 2021-2025 Lessons



# Conclusions and recommendations: fundamental priorities



The implementation of the MTS 2021–2025 according to four fundamental priorities is a relevant model corresponding to the value chain of cancer research and prevention. This organization is also in line with the four Pillars of IARC gathering the scientific competences in the Branches.

### Fundamental priority #1: Data for action

According to the MTS 2021–2025, the first fundamental priority of the MTS aims to "collate, analyse, evaluate, and disseminate cancer data for the benefit of the wider cancer community as a means of informing global cancer control and research". This priority represents an IARC flagship programme.

### **Achievements:**

- ✓ Enhanced global cancer data dissemination: During the 2021–2024 period, the CSU Branch, the primary contributor to this priority, successfully developed and disseminated its flagship databases and publications, including GLOBOCAN 2022 and Cancer Incidence in Five Continents (CI5). These outputs were made available through the Global cancer Observatory (GCO), a vital resource for cancer surveillance.
- ✓ Strengthened global cancer registry development: The Global Initiative for Cancer Registry Development (GICR) further consolidated its activities, improving the collection and quality of cancer data worldwide. These efforts form the critical first link in the value chain of cancer research and control, enabling evidence-based action globally.
- ✓ Exceptional scientific impact: The bibliometric analysis of the MTS highlights the exceptional citation levels associated with CSU programmes, reflecting their global relevance. CSU's data on cancer surveillance support numerous IARC scientific projects and partnerships and strengthen collaboration with WHO headquarters, particularly on the WHO global cancer initiatives.
- ✓ Recognized core mission contribution: The 2022 CSU Branch Review underscored that these activities, despite being underfunded, are core to IARC's mission and benefit from a strong and long-standing reputation.

### **Recommendations:**

Although this priority has achieved significant success, limitations were identified in **health economics**, particularly in realizing the MTS's stated ambition to "expand IARC activities in health economics and cancer, by measuring the economic burden and socioeconomic inequalities in cancer integrating economic data into the GCO, evaluating the impact, cost, and feasibility of country–specific priority interventions (...). Using the WHO headquarters costing tool, which is under development, a series of scenario–based research studies will seek to quantify the public health and economic impacts of implementing effective preventive measures in different settings".

- → IARC is encouraged to support and fund activities within Pillar 1 dedicated to health economics and cancer,
- → This Branch should work closely with EPR to consolidate existing IARC research in health economics, modelling, and social inequalities, while integrating additional scientific resources and partnerships.
- → This investment would enhance IARC's ability to demonstrate the **public health and economic benefits** of cancer prevention measures to **policy makers and health authorities**, strengthening the case for effective interventions to reduce the cancer burden.

# Fundamental priority #2: Understanding the causes

According to the MTS 2021–2025, "understanding the mechanisms and causal pathways of cancer development is critical for the conception and implementation of effective interventions, and to realize a world where fewer people develop cancer. Likewise, it is important to identify and evaluate key risk factors, in particular modifiable ones, and enhance the understanding of how these affect the cancer burden".

### **Achievements:**

- ✓ **High-performing scientific Branches:** The GEM and NME Branches are the primary contributors to this priority, with additional contributions from EGM and ENV. These Branches rely on resources such as the EPIC cohort (see case study in appendices) and IARC's unique Biobank, enabling an impressive volume of publications in leading scientific journals, as reflected in the MTS bibliometric analysis. In addition, they have successfully fostered synergies within the Pillar.
- ✓ The 2021 GEM Branch Review highlighted the Branch's **extensive international partnerships**, such as the Mutographs project (see case study in appendices).
- ✓ GEM has been successful in securing substantial **external funding**, demonstrating productivity in both primary and secondary prevention across various cancer sites.
- ✓ GEM has made significant contributions to **computational expertise** at IARC, including the creation of the IARC Scientific IT platform (see case study).
- ✓ The 2023 NME Branch Review recognized the Branch as multidisciplinary, demonstrating international leadership and exceptional productivity.
- ✓ NME plays a pivotal role in maintaining and advancing the EPIC study, ensuring that it remains state-of-the-art and addressing important research questions with cutting-edge methodologies. This work is supported by a team of outstanding scientists and extensive collaborations both within and beyond IARC.
- ✓ NME's work in LMICs underscores its strategic positioning to conduct globally impactful research, with NME's leading role in three case—control studies on nutrition, lifestyle, and breast cancer in Morocco, South Africa, and Latin America.

# ations:

### **Recommendations:**

Given its leadership of major international cohorts, IARC is uniquely positioned to:

- → Leverage its expertise in **data pooling** and **federated analysis** to integrate diverse datasets.
- → Establish and manage **consortia of international cohorts**, creating opportunities for large-scale cancer research supported by **omics technologies**.
- → Consider a strengthened One Health approach in coordination with Pillar 3 (ENV) to promote comprehensive strategies for healthier environments and populations.

### Fundamental priority #3: From understanding to prevention

According to the MTS 2021–2025, "transforming knowledge about cancer causes and risk factors into evidence-based preventive interventions that can inform policies to save lives is central to IARC's mission". The research activities related to fundamental priority 3 focus on three types of interventions: "primary prevention of established modifiable risk factors, secondary prevention by screening of asymptomatic at-risk populations, and early diagnosis of common cancer types in symptomatic individuals, to improve survival and quality of life after treatment".

- ✓ Key contributing Branches: The primary contributors to this priority are the ENV and EPR Branches, with additional contributions from the EGM Branch.
- ✓ The 2022 ENV Branch Review recognized ENV scientists as international leaders with extensive expertise and strong collaborative networks within and beyond IARC.
- ✓ ENV has demonstrated outstanding contributions to public health, policy, and clinical practice, supported by its prolific publication record.
- ✓ ENV has successfully established several valuable collaborative networks in cancer research, with significant engagement from LMICs.
- ✓ The EPR Branch Review is scheduled for 2025. Its self-assessment highlights a broad geographical diversity in projects, with a focus on LMICs, contributions to national and international policies and guidelines, and research outcomes with significant public health impact, such as evidence supporting single-dose HPV vaccination.
- The MTS evaluation KPIs show that EPR has been highly effective in sourcing external funding, raising €23 million in 2021–2023.
- ✓ The EGM self-assessment has outlined a roadmap for maximizing the Branch's potential, highlighting opportunities to strengthen synergies with other Branches and align more closely with IARC's strategic objectives. The upcoming EGM Branch Review, scheduled for early 2025, will further refine these insights and guide the Branch's direction.



### **Recommendations:**

### Strategic evolution of EGM Branch:

- → With an upcoming leadership transition in the EGM Branch, IARC is encouraged to develop a new structure for EGM's scientific programmes, ensuring stronger synergies with Branches in Pillars 2, 3, and 4.
- → This reorganization should integrate the conclusions of the 2025 Branch Reviews and align with the MTS 2026–2030 priorities.
- → Particular focus should be placed on consolidating research on **epigenetic biomarkers of childhood cancers** (refer to the **EpiChildCan case study** in the appendices).

#### Integration of WHO strategic objectives:

→ Branches in Pillar 3, especially ENV, are advised to incorporate the WHO Fourteenth General Programme of Work (GPW 14) priorities for 2025–2028, which highlight climate change as a strategic priority. The GPW 14 considers climate change as the greatest health threat of the 21st century, and its impacts (air pollution, water pollution, chemical pollution, epidemic diseases, migration and demographic shifts, evolution of food systems, etc.) also affect cancer and NCDs.

# Fundamental priority #4: Knowledge mobilization

According to the MTS 2021–2025, "scientific evidence and information generated through IARC's work, including about cancer occurrence, classification, causes, hazards, effective interventions, and potential preventive means, must be made available in a timely manner to relevant experts, authorities, and decision-makers. In addition, national capacities to implement the evidence-based intervention must be strengthened, to ensure that advanced global knowledge about cancer is translated into a public health impact".

- ✓ Although all scientific Branches contribute to this ambition, the **ESC Branch** is at the forefront with its three IARC flagship programmes: **IHB, IMO, and WCT**.
- ✓ The 2024 ESC Branch Review commended the Branch for its outstanding scientific quality, productivity, and leadership. ESC's programmes generate globally authoritative bodies of evidence and establish international standards that are critical for reducing the global cancer burden.
- ✓ The Branch Review recognized ESC's **remarkable vision and unique contributions**, delivering evidence of the **highest quality**, essential for public health and policy impact. A key challenge identified for ESC is the need to **diversify the funding** for the **Monographs programme** to safeguard its **independence and sustainability**.
- ✓ Cross-cutting support from LCB: LCB plays a vital role in addressing global capacity challenges, especially in resource-limited settings, by supporting all IARC scientific Branches in learning, training, events, and capacity-building activities and organizing the IARC Summer School and hosting an average of 130 ECVS each year at the Agency.



### **Recommendations:**

→ Strengthen training programmes through WHO Academy partnership: Building on the partnership established in 2023 with the WHO Academy, the LCB Branch should work to enhance synergies with WHO headquarters and expand the scale and reach of training programmes, focusing on cancer prevention in LMICs and globally. This collaboration offers an opportunity to deploy IARC's training resources on a new scale, significantly increasing their public health impact.

# Conclusions and recommendations: emerging priorities

# **Emerging priority #1: Evolving cancer risk factors and populations in transition**

Evolving cancer risk factors and populations in transition is the first emerging priority of the MTS 2021–2025: "IARC's pertinent competences are its descriptive epidemiological work, in particular the study of cancer incidence attributable to relevant risk factors; its etiological research with population-based and experimental studies; and its multidisciplinarity, which facilitates studies into multidimensional exposures to risk factors and their interdependency."

### **Achievements:**

- ✓ Cross-Branch contributions: All IARC scientific Branches contribute to research on evolving cancer risk factors, with NME in Pillar 2 serving as the major contributor through:
  - o the Lifestyle Exposure and Interventions Team (LEI),
  - o the Nutrition, Cancer, and Multimorbidity Team (NCM),
  - o the Hormones Team (HorM),
  - o the Onco-Metabolomics Team (OMB),
  - o the Population-Based Long-Term Surveillance (LTS) IARC-Japan Team.



### **Recommendations:**

→ As part of the preparation for the MTS 2026–2030, IARC is encouraged to integrate this emerging priority into the Pillar 2 roadmap, ensuring a structured and focused approach to evolving cancer risk factors and populations in transition.

### **Emerging priority #2: Implementation research**

Implementation research for cancer prevention is defined in the MTS 2021–2025 as the scientific study of the processes, tools, and methods used to implement cancer prevention interventions as well as the relevant contextual factors. The successful adaptation and scaling up of such interventions depend on the local context and health system capacities, on the availability of adequate human, financial, and infrastructural resources, and on the availability of relevant and high-quality population-based data.

### **Achievements:**

- ✓ Establishment of the Research for Implementation (RFI) Team: In February 2024, IARC launched the Research for Implementation (RFI) Team, dedicated to closing the gap between scientific evidence and public health decision-making.
- ✓ The RFI Team applies scientific principles, methods, and theories to the entire implementation process, ensuring that efforts are rigorous, effective, and evidence-based.
- ✓ The Team is coordinated by scientists from the EPR Branch and supported by contributions from CSU, ENV, and LCB colleagues.



### **Recommendations:**

→ For the next MTS (2026–2030), IARC should recognize implementation research as a priority within Pillar 3.

# **Emerging priority #3: Economic and societal impacts of cancer**

The third emerging priority of the MTS 2021–2025 addresses a double challenge: economics of cancer and cancer inequalities. Research in health economics targets the systematic description of the economic burden of cancer and the generation of evidence and tools to inform national policy-making and resource allocation related to cancer prevention. As mentioned before, the IARC Research Teams on this topic did not materialize during the 2021–2024 period.

The second challenge of this third emerging priority of the MTS concerns cancer inequalities, because the cancer burden is not equally distributed across countries, within countries, and between different groups within societies. The structural determinants of health are the social and economic conditions in which people are born, live, work, and age. The definition and implementation of cancer prevention policies need to integrate those cancer disparities to be more effective.

- ✓ **Dedicated efforts on cancer inequalities:** The Cancer Inequalities Team (CIN), coordinated by the CSU Branch, is fully dedicated to addressing this challenge.
- ✓ The team focuses on measuring and monitoring social inequalities in cancer and comparing these inequalities across populations within the broader context of the global epidemiological transition of cancer.
- ✓ CIN also examines **inefficiencies in health-care service provision**, contributing critical insights to guide policy interventions.



### **Recommendations:**

Despite the importance of health economics, the formation of dedicated IARC Research Teams on this topic did not materialize during the 2021–2024 period. To address both challenges effectively, IARC is encouraged to:

Consolidate its activities on health economics and cancer inequalities currently conducted within CSU and EPR, while reinforcing synergies between these efforts.

# Conclusions and recommendations: cross-cutting collaborations and Research Teams

The MTS bibliometric analysis revealed that co-publications across IARC Branches (with at least 2 co-authors from 2 separate Branches) represent only 7% of IARC's scientific production for the 2021–2024 period. The collaborations of scientific Branches should clearly be reinforced within and across Pillars. This implies that IARC should encourage synergies across Branches and Pillars by implementing a matrix organization. Those synergies should be supported by the Research Teams and the research infrastructures.

### The IARC Research Teams

The concept of IARC Research Teams was developed to facilitate the scientific work within and across IARC's research Branches by reducing the silo approach within Branches and introducing a more flexible modality of scientific collaboration on closely related research, in order to better implement the MTS 2021–2025. Teams are informal organizational units within a research Branch or across Branches. The main task of a Team is to manage the implementation of two or more thematically related research or technical projects towards a common goal. The creation of Teams is based on needs and added value. For the 2021–2024 period, the Research Teams were organized according to the following 7 categories: WHO Global Initiatives, Cancer-Focused, Functional Cancer Genomics, Metabolism, Methodological Innovations, Cancer in Informative Populations, and Cancer, Public Health, and Society.

The evaluation of the MTS 2021–2025 confirmed the benefits of the Research Teams model, highlighting their capacity to support IARC's mission and strategic goals:

- ✓ Improved visibility and communication: Enhanced awareness and understanding of IARC's scientific projects across the Agency, relying on a bottom-up approach to research focus.
- ✓ Strengthened collaboration across Branches: Facilitated cooperation among IARC Branches, reducing silos and contributing to the value chain of cancer research.
- ✓ Targeted external collaborations: Strengthened partnerships with external scientific collaborators, aligning with IARC's global goals.
- ✓ Structured cooperation with WHO: Enabled better collaboration with WHO headquarters, especially on the WHO global cancer initiatives.
- ✓ **Optimized grant applications:** Improved coordination and preparation of grant proposals with contributions across the Agency.
- ✓ **Fostering innovation**: Provided a platform for exploring innovative scientific concepts and preparing future IARC scientific programmes.
- ✓ Opportunities for early-career scientists: Allowed early-career scientists to take on leadership roles in project implementation within Teams.



### **Recommendations:**

- → Strengthen the Research Teams model: Reinforce the Research Teams as a new dimension of IARC's organization, ensuring that they continue to reduce silos, foster collaboration, and align with the Agency's strategic priorities.
- → Define new Terms of Reference (ToR): Update the ToR for Research Teams to solidify the bottom-up approach and categorize Teams into: Innovations Teams for emerging scientific concepts and methodologies, and Cancer-Focused Teams aligned with IARC's mission and the WHO global initiatives on cervical, childhood, and breast cancers.
- → Expand current Cancer-Focused Teams: Build on existing Teams dedicated to cervical cancer (CCEI), childhood cancer (GICC/WIT2C), breast cancer (GBCI), gastric cancer (GCP), oral cancer (OCT), and oesophageal cancer (ECA).
- → Align Cancer-Focused Teams with LMIC priorities: Ensure that Cancer-Focused Teams align with GLOBOCAN 2022 data on the cancers with the highest incidence and mortality in LMICs, such as:
  - o Lung cancer
  - Colorectal cancer (including early-onset colorectal cancer)
  - Liver cancer
  - Prostate cancer.
- → Invest in LMIC research: Direct specific investments to ensure that Research Teams address cancers that disproportionately affect LMICs, emphasizing research and prevention strategies tailored to these regions.

### **Research infrastructure**

The IARC research infrastructure consists mainly of the biobank, the pathology laboratory, the laboratory services, and the Scientific IT platform. According to the MTS 2021–2025, "in the Nouveau Centre, laboratory services will be provided centrally to research teams". Officially attached to NME, the Laboratory Support, Biobanking, and Services (LSB) unit, which manages the biobank, is a cross-cutting function of IARC, working with all Pillars and some external partners.

### **Achievements:**

- ✓ Biobank achievements: The successful IBISA application of the IARC Biobank in 2023 underscores IARC's commitment to building an Open Science biobank with quality management and certification standards. This initiative enhances IARC's ability to facilitate scientific collaboration both within the Agency and with external partners.
- ✓ **Scientific IT platform**: The creation of the **Scientific IT platform**, designed as a shared digital infrastructure, represents another significant milestone, fostering interactions between research personnel and external collaborators.
- ✓ Laboratory organization supporting multiple IARC Branches: IARC's laboratories are managed by various Branches and organized as follows:
  - Histopathology: ESC Branch.
  - Metabolomics and immuno-assays: NME Branch.
  - Genomics: GEM, EGM, and EPR Branches.
  - Virology: EPR and GEM Branches.
  - Cell cultures: EGM and EPR Branches.
  - The Laboratory Steering Committee (LSC) ensures operational coordination across these diverse activities.



### **Recommendations:**

The IARC laboratories are not yet organized as shared research infrastructure, based on Open Science. IARC is invited to:

→ Develop a unified strategy and management for shared research platforms: Build on the successes of the IARC Biobank and the Scientific IT platform to establish a comprehensive strategy for shared research platforms, ensuring alignment with the needs of IARC scientific Branches and external partners, and improving their visibility for reinforced collaborations.

As highlighted in the MTS 2021–2025, "IARC's laboratory services will continue to generate global standards and best practices in laboratory activities and biobanking. For example, in collaboration with the International Organization for Standardization (ISO), IARC will disseminate relevant information to the research community about these best practices, thereby strengthening global laboratory practice". To uphold this commitment, IARC is encouraged to:

→ Implement ISO quality standards internally in the short term, prioritizing ISO 20387 certification on biobanking and ISO 9001 NFX 50-900 certification for laboratories. By achieving these certifications, IARC will not only enhance the quality and credibility of its operations but also position itself as a global leader in promoting quality guidelines across the international scientific community.