External Evaluation of the International Agency for Research on Cancer (IARC)

Final Report by the ad hoc Advisory Group

24 November 2019

#### **Executive Summary**

The Governing Council of IARC, with support of the Scientific Council, commissioned an independent evaluation by an ad hoc Advisory Group to cover six areas:

- (a) the alignment of IARC's activities with its mandate, as described in the Statute and the prioritization of different areas;
- (b) the collaboration between IARC and other parts of WHO to ensure clear definition of roles and effective cooperation and coordination;
- (c) the contribution of multi-disciplinary research to IARC's strategy, including the balance of laboratory equipment in-house and accessed through external collaboration;
- (d) the role and infrastructure for the biobank in IARC's research strategy;
- (e) mechanisms to ensure the financial sustainability of IARC's research including the laboratory research and biobank; and
- (f) approaches to maximize the value and impact of IARC's work.

The Advisory Group assembled to undertake this evaluation included two members of the Governing Council, two members of the Scientific Council, and five internationally recognized leaders in cancer prevention research. The Advisory Group met several times and was supported in its work by the evaluation office of the World Health Organization (WHO). The evaluation included the review of key documents, as well as interviews and surveys conducted with Governing Council and Scientific Council members and IARC and WHO staff.

The Advisory Group acknowledges the clear impact and productivity of IARC, which it has been able to achieve even under the difficult circumstances of its significant funding uncertainties. However, despite the clear planning process and structures that are in place, the Advisory Group noted that further opportunities to sharpen prioritization and use of its resources can be identified and pursued.

Based on an extensive review and in-person discussion over two days in mid-October 2019, the Advisory Group made ten recommendations, detailed in the report, for IARC to take action in order to address the need for:

- a more inclusive, transparent and focused strategic prioritization process during the development of the MTS 2021-2025;
- strengthened collaboration between IARC and WHO, in particular with WHO's newly established Science Division, and with those at WHO involved in the public policy implications of cancer research results;
- assurance that efforts currently underway to synchronize the IARC Governing Council and the WHO Executive Board meetings are realized;
- a future-focused consideration of which core in-house laboratory capacities should be incorporated into the Nouveau Centre building and which are best obtained through collaborations with external laboratories to maximize efficiencies;
- regular updates to the Scientific Council and Governing Council on the ongoing computational and data storage needs for bioinformatics into the future;

- intensified efforts to obtain additional laboratory, bioinformatics, and other disciplinary expertise through collaboration, Visiting Scientists, and secondments from Participating States and other partners;
- enhanced biobank capacity to fulfil IARC's global role;
- an assessment of whether its collection of biological samples is optimal in view of IARC's global mission; and
- a range of activities to ensure the future financial sustainability of its research through strengthened budgeting, communications and resource mobilization.

The Advisory Group acknowledges that IARC has already undertaken important steps to address several aspects of these recommendations. It also recognizes that the MTS 2021-2025 development process serves as a key platform for shaping IARC's future in the medium term. The Advisory Group thus encourages IARC to seize on this process as an opportunity to strengthen or accelerate momentum on those actions already underway – and for actioning the Advisory Group's additional recommendations.

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# Background

- 1. At its 60<sup>th</sup> Session in May 2018, the Governing Council of the International Agency for Research on Cancer (IARC) considered a proposal to undertake an independent external evaluation of IARC (document GC/60/12), the result of which would serve as one integral input into the development of the Medium-Term Strategy (MTS) 2021-2025. In resolution GC/60/R11, passed at the conclusion of this same session, the Governing Council requested the evaluation be carried out, and that the IARC Secretariat prepared a document describing the scope and terms of reference for the evaluation to be discussed at the Scientific Council and be submitted to the Governing Council for consideration and approval.
- 2. The Scientific Council, at its 55<sup>th</sup> session in January-February 2019, discussed and supported the proposed parameters of the evaluation described in the document *Procedure for the preparation of the IARC Medium-Term Strategy (2021-2025), including an evaluation of IARC* (document SC/55/7).
- 3. The Governing Council, at its 61st session in May 2019, reviewed and endorsed the revised parameters of the evaluation that incorporated inputs from the Scientific Council, document GC/61/8. Through resolution GC/61/R7, an ad hoc Advisory Group comprised of external experts, Governing Council and Scientific Council members was established to conduct an evaluation of IARC, covering the six areas as follows:
  - A. the alignment of IARC's activities with its mandate, as described in the Statute and the prioritization of different areas;
  - B. the collaboration between IARC and other parts of the WHO to ensure clear definition of roles and effective cooperation and coordination;
  - C. the contribution of multi-disciplinary research to IARC's strategy, including the balance of laboratory equipment in-house and accessed through external collaboration;
  - D. the role and infrastructure for the biobank in IARC's research strategy;
  - E. mechanisms to ensure the financial sustainability of IARC's research including the laboratory research and biobank; and
  - F. approaches to maximize the value and impact of IARC's work.
- 4. The Governing Council, in its 61<sup>st</sup> session, further stipulated that the evaluation "could be conducted through a mixture of review of IARC reports and documents, an online survey open to all IARC Participating States through Governing Council and Scientific Council members, and questionnaires to the concerned units at the WHO and to IARC staff …" In addition, the Advisory Group decided to meet first to plan its work (including the selection of a Chairperson and agreement on the division of labor, decision-making procedure, and other practical protocols to guide the process), and then again to report on progress. (See GC/61/8, paras 30-31.)

# **Evaluation approach**

- 5. The Advisory Group convened its first meeting on 15 July 2019 and agreed to the overall evaluation approach. The WHO Evaluation Office was requested to support the Advisory Group in its work in order to ensure adherence to the technical evaluation standards as well as the normative principles set forth in the United Nations Evaluation Group (UNEG) norms and standards. Two consultants were contracted to undertake data collection and analysis under the guidance and supervision of the WHO Evaluation Office. The Head of the WHO Evaluation Office and the Chief Evaluation Officer each dedicated supervision and guidance to the evaluation on a part-time basis, and enlisted technical assistance by recruiting two consultants (one full-time, one part-time). Together, these four individuals constituted the evaluation support team referenced in this report.
- 6. The Advisory Group convened its second meeting on 9 September 2019 to obtain status updates from the evaluation support team on the evaluation's progress and to discuss next steps. It convened its final meeting on 18-19 October 2019 to discuss the findings and conclusions of the evaluation support team and to agree on a way forward for the drafting of this report, including the formulation of its recommendations.

#### Scope and methods

- 7. The scope of this evaluation was predetermined by the Governing Council and the Scientific Council, as per para 3. The methods were further specified as encompassing "a mixture of review of IARC reports and documents, an online survey open to all IARC Participating States through GC and SC members, and questionnaires to the concerned units at the WHO and to IARC staff." Within these parameters, the evaluation support team, with the agreement of the Advisory Group at its 15 July meeting, undertook an inception mission to Lyon from 5-9 August 2019, with a view to:
  - deepening the evaluation team's understanding of the key issues subsumed under each of the six areas covered in the evaluation;
  - establishing a communication channel with key stakeholders at an early stage of the exercise, thus helping to promote a constituency for the evaluation and the foundation for future uptake of its analysis;
  - identifying the key stakeholders to target with each of the data collection modalities;
  - culling key background documentation for the desk review component of the evaluation; and
  - developing the content of the specific data collection instruments.

Toward this end, the evaluation support team conducted inception interviews by telephone with all 10 Advisory Group members, and with 17 senior staff of IARC (some in person, others remotely). The evaluation team additionally met with the Director and her senior management team several times throughout the inception mission to clarify issues as these arose.

8. Data collection proceeded immediately after the inception phase and, as per the methods prescribed in document GC/61/8 and agreed by the Advisory Group at its 15 July meeting,

including the following specific data collection modalities, the specific content of which was informed by the interviews and desk review conducted during the inception phase:

- Desk review of key documents. A total of over 40 documents, identified during the inception phase, were reviewed in depth. In addition to foundational documents such as the IARC Statute, Rules and Regulations and relevant Governing Council and Scientific Council reports and resolutions, these included: strategic planning documents (e.g., the MTS 2016-2020, procedures for the preparation of the MTS 2021-2025, evaluation report on the implementation of the IARC MTS 2016-2020); programme and budget documents (e.g., proposed and approved Programme and Budget 2020-2021, the Coordinated Resource Mobilization Strategy 2016-2020, IARC donor mapping overview, terms of reference for the Strategic Engagement and Resource Mobilization Officer); information related to the biobank, laboratory and analytical computing facilities (e.g., the Genetics Platform (GPS) Operational Model, the IARC Strategy and Plans for Bioinformatics SC/53/8); information on partnerships, cooperation and communication (e.g., the Communications Strategy, terms of reference for the IARC Liaison Officer to WHO, GC/60/30 Coordination and Communication Mechanisms between IARC and WHO - at Management and Working Level); consolidated excerpts from Scientific Report of Section Reviews conducted from 2015-2019; and more.
- Online surveys with Governing Council and Scientific Council<sup>[1]</sup> members. An online survey, identical in content for both bodies and including both closed- and open-ended questions covering each of the six areas prescribed for the evaluation, was deployed to all Governing Council and Scientific Council members in English and French on 28 August 2019. Reminders were sent on 9 September, 13 September and 17 September 2019. The survey was officially closed on 16 September 2019, but completed surveys continued to be submitted until 22 September 2019. All completed surveys were included in the analysis.
- Key stakeholder interviews with IARC and WHO staff. Semi-structured interviews were conducted with senior-level IARC staff, as well as senior-level WHO staff identified by the evaluation support team in consultation with IARC staff during the inception phase, from 2-30 September 2019. WHO staff included those individuals who have worked with IARC colleagues previously, as well as members of WHO's senior leadership team who are familiar with the issues covered in the evaluation.
- Online questionnaire for IARC staff. An online survey, closely mirroring the Governing Council and Scientific Council member survey and likewise including both closed- and open-ended questions covering each of the six areas prescribed for the evaluation, was deployed to all IARC staff in the professional staff categories (P-level and above) and selected former IARC staff on 28 August 2019. A reminder was sent from the WHO Evaluation Office on 4 September 2019 and another from Director IARC on 13 September. The survey was officially closed on 17 September 2019.

<sup>&</sup>lt;sup>[1]</sup> Given the change in specific individuals on the Scientific Council during the evaluation, only those individuals departing the Scientific Council – that is, those with greater familiarity with the issues at hand – were targeted in the survey.

• Online questionnaire for WHO staff. A shorter questionnaire was sent to key WHO staff (those identified by IARC staff as having worked with IARC), based closely on the IARC staff questionnaire but modified to exclude questions less salient to WHO colleagues. The survey was deployed on 28 August 2019. Reminders were sent on 4 September and 9 September 2019. The survey was officially closed on 11 September 2019.

Confidentiality was guaranteed in all of these data collection modalities and, as much as possible, questions remained identical across the stakeholder-specific surveys and interview guides and for optimal benchmarking of various stakeholder groups' perspectives in relation to each other. Table 1 provides an overview of these data collection modalities included in the revaluation.

Key Stakeholder Interviews	Number Targeted	Number Undertaken	
IARC staff	12	12	
WHO staff	9	9	
Surveys and Questionnaires	Number Targeted	Number Received	<b>Response Rate</b>
Governing Council members	27	17	63.0%
Scientific Council members	27	14	51.9%
IARC staff	90	64	71.1%
WHO staff*	14	2	14.3%

#### Table 1 – Overview of Interviews and Surveys/Questionnaires

\* Owing to the low response rate, and the need to ensure confidentiality of the information gathered, the data from the two WHO staff surveys were folded into the analysis of the WHO key informant interviews.

#### Limitations

- 9. Throughout both the inception and data collection phases, the evaluation support team received frank, constructive and helpful information from all interviewees. It also enjoyed the full cooperation of IARC, including the Director, as well as excellent administrative and logistics support in the conduct of its work. There were therefore no fundamental limitations to the evaluation support team's work from the standpoint of cooperation or information availability.
- 10. One technical issue revolved around the low response rate on the Scientific Council surveys despite repeated follow-up reminders. However, 20<sup>1</sup> of the 27 members of Participating States completed either the Governing Council survey, the Scientific Council survey, or both, thus ensuring that participation in the evaluation by Participating States was sufficiently broadbased. In addition, several Participating States, upon completion of their respective surveys, indicated that the feedback they had provided represented the comments of both their Governing Council and Scientific Council representatives. With respect to the WHO staff questionnaire, this challenge was overcome by folding the survey data received into the WHO staff interview analysis.

<sup>&</sup>lt;sup>1</sup> The delegation of the Netherlands to the Governing Council provided comments separately in an email dated 31 October 2019 – after the data analysis was completed and the Advisory Group conducted its final meeting. This feedback, which is consistent with that of numerous other Governing Council members, was subsequently incorporated into the analysis and the finalization of this report.

- 11. A further challenge revolved around the potential selection bias in the WHO staff included in interviews and questionnaire, who were those who had perspectives on IARC because of their familiarity with it. Not included were those WHO staff who might not have worked directly with IARC but might nonetheless have had perspectives on the potential for future collaboration between the two entities. Given the scope and objectives of this evaluation, this limitation did not pose a significant barrier to the analysis, however.
- 12. One final challenge revolved around the volume of data, and particularly the number of documents to be included in the evaluation, given the very limited timeframe for completing the evaluation. It was not possible, for example, to review all project proposals or even a representative sample of such proposals to gauge their alignment with IARC's mandate, or to include any number of otherwise relevant documents in the desk review. Only those documents most necessary for making reasonably well-informed analysis of the six topics at hand were prioritized, rather than delving into every possible document that might otherwise have shed light on each of the topics if more time and resources had been available.

# **Evaluation findings**

- A. Alignment of IARC's activities with its mandate, as described in the Statute and the prioritization of different areas
- 13. The IARC Statute articulates the agency's objectives as being to "promote international collaboration in cancer research ... The agency ... may cooperate in the stimulation and support of all phases of research to the problem of cancer." Article II furthermore indicates that the agency "shall make provision for planning, promoting and developing research in all the phases of the causation, treatment and prevention of cancer." Article II also stipulates that if the Secretariat chooses to carry out "special projects"<sup>2</sup>, it may do so upon the specific approval of the Governing Council based on the recommendation of the Scientific Council. The desk review and interviews conducted in this evaluation revealed that, within its broad mandate to undertake research on the causation, treatment and prevention of cancer, IARC has prioritized research on causation and prevention to date rather than treatment.

## Alignment of MTS to the mandate

14. The first level of alignment examined in this evaluation was that between the Statute and IARC's overarching strategic planning document, the Medium Term Strategy (MTS) 2016-2020. The MTS is intended to translate the agency's mandate into a concrete set of strategic priorities, articulating a rationale for these choices in accordance with the mandate. Given the large number of institutions that undertake cancer research globally, the MTS, like any other

<sup>&</sup>lt;sup>2</sup> "Special projects" refer to projects that are complementary to the permanent/core programme financed or pilot studies, mostly funded from voluntary contributions; they are submitted to GC for approval each year.

form of strategic planning document, represents a platform for articulating IARC's strategic priorities with a clear view to its comparative advantage (or value proposition) in relation to these other actors – that is, not only in terms of whether these priorities are *consistent* with its mandate but rather also whether, in the face of limited resources, they are those that are *most closely aligned* with its mandate and those that *most clearly capitalize on its comparative advantage*.

- 15. In this vein, the desk review determined that the MTS 2016-2020 does indeed represent a clear set of strategic priorities which at face value are consistent with IARC's mandate as formulated in the Statute. However, the desk review also revealed that the MTS does not clearly articulate a rationale for its strategic choices those areas it will prioritize because they are the *most* consistent with its mandate and *most* in keeping with its comparative advantage compared to other institutions in the international cancer research field. The focus areas laid out in the MTS are governed by overarching principles (e.g., IARC's international status, its independence, expertise, reputation and networks), and it does demarcate its focus on prevention by stating that countries cannot "treat" their way out of the global cancer epidemic. However, the MTS does not explicitly formulate IARC's comparative advantage as the basis for its strategic choices in the first instance.
- 16. All interviewees and most respondents from all stakeholder groups were able to mention specific facets of this comparative advantage, but in very few cases was a clear, concise articulation of IARC's comparative advantage voiced. The evaluation nonetheless identified numerous such aspects of IARC's niche in relation to other cancer research institutions globally. These include IARC's independence (i.e., its lack of encumbrance by commercial interests in the development and implementation of its research), its impartiality, high integrity and ethical standards, and its ability to recruit leading cancer research scientists.
- 17. One specific area of comparative advantage cited by many stakeholders is the extent of IARC's global collaboration and its international scope and reach (including its relationship with WHO, whose visibility and influence in the public health policy realm, was also cited, although this specific collaboration remains an area not yet fully exploited; see Part B). As a "stimulator" and catalyst of cancer research, IARC focuses on partnerships and collaboration across countries and organizations for upstream research work. As such, it is well suited to lead, coordinate and participate in multi-center, transnational studies, providing informed, independent oversight to complex projects and widening the scope of its scientific coverage. In this vein, IARC's global mandate as an international organization also allows it to study cancer anywhere in the world, providing valuable information for cancer control across many different settings which other cancer research institutions cannot readily access. One particularly notable aspect of this angle is that, through the development of research platforms, collaborative research – including in Low- and Middle-Income Countries (LMICs) the development of bio-banking – is more readily possible for IARC than for less internationally focused research institutions. Since the development of research capacity around the world is central to IARC's mission through its robust training programme, it delivers capacity building activities in a variety of programmes. Furthermore, through joint studies it effectively provides on-the-job training for participant scientists from LMICs. On returning to their home countries these scientists help lay the ground for future collaborative research efforts.

- 18. Another source of IARC's comparative advantage, stemming in part from this unique global reach, is its unique capacity to synthesize the findings of cancer research in publications with worldwide circulation and acceptance, such as the Monograph and Bluebook & Handbook series. Through its rich and diversified publications and dissemination programme, IARC thus provides public goods to the international community which are widely used and referenced. Importantly, as international public goods, these publications are also available to LMICs, as is its support to cancer registries in the adaptation of research tools for assessing the risk factors of carcinogenic agents; in these ways, the agency is providing support to cancer control planning globally.
- 19. Despite these top-of-mind associations with IARC, its comparative advantage is not universally viewed as being clear or clearly articulated, either in the MTS or in external communications. (See Part F.) As noted above, the MTS is generally viewed as a forward-looking planning instrument and a platform for the prioritization of the agency's activities.

#### Alignment of projects with the MTS: the Project Tree

- 20. The second level of alignment examined in this evaluation centered on that between IARC's Project Tree (an appendix to the MTS) and the MTS. The Project Tree, a diagrammatic presentation of IARC's activities and related organizational units, is structured horizontally in Level 2, 3, 4 Objectives and Project Budget Proposals (59 Projects for the current MTS), with each of the objectives levels being progressively more granular in detail, leading to the collaborating organizational units: Sections and Groups. Vertically, the Project Tree lays out the six key priority areas under Level 2 Objectives.<sup>3</sup> Given the broad mandate in the Statute and based on the congruence of the formulation of the disaggregated sequence, alignment among Levels 2, 3 and 4 Objectives is implied.<sup>4</sup>
- 21. The project tree is a critical appendix to the MTS, as it lays out in a sequential order the different areas of focus, leading up to the repertoire of projects which is the core of IARC's activities. The designation of Project<sup>5</sup> is used for planning and budgeting purposes only. As shown in the project tree, these projects usually require inputs from multiple units of IARC, creating a high level of interdependence among these units and making for a challenging dynamic of collaboration and tracking of staff time by projects.<sup>6</sup> Measuring progress or productivity of these on-going activities is a challenge because they do not seem to have measurable milestones of progress or relation between inputs and outputs. Instead, project descriptions start with open-ended designations such as: "expand, improve, advance, increase, enhance", reflecting the on-going nature of such "projects".
- 22. The MTS seems to reflect the ongoing pattern of IARC objectives along the lines of the 6 leveled objectives and projects, shown in the Project tree and serves as a bridge between the

<sup>&</sup>lt;sup>3</sup> The highest level of Objectives aggregation

<sup>&</sup>lt;sup>4</sup> As noted in para 12, given the limited time allocated to this evaluation, the team was not able to systematically examine individual project proposals to assess their consistency and alignment with the Objective and Functions of the Statute or with the Level of Objectives sequence. <sup>5</sup> A project is a discrete (i.e. individually distinct) planned activity which has specific objectives, a clearly definable beginning, and a clearly

<sup>&</sup>lt;sup>•</sup> A project is a discrete (i.e. individually distinct) planned activity which has specific objectives, a clearly definable edu definable edu (i.a.c. PROCE AMME AND RUDGET 2018 2019; Guide for Preparation and Submission of Project and Budget Proposals

<sup>&</sup>lt;sup>6</sup> IARC PROGRAMME AND BUDGET 2018-2019: Guide for Preparation and Submission of Project and Budget Proposals

mission and vision of IARC and its programmatic structure. It is also noteworthy that the 2016-2020 MTS is part of a long-term plan developed in the previous MTS 2010-2015 which included reorganization of some of its operational units.<sup>7</sup> Furthermore, this MTS focuses more on areas of increased recent emphasis such as cancer burden, evaluation of preventive interventions and the advances in molecular sciences in relation to epidemiological studies, which are not necessarily treated as priority areas.

- 23. To better understand how priorities are reflected in the MTS and the Project tree, it is important to note that criteria for prioritization and choice of focus areas vary according to the instrument, and emphasis is rather on sequencing. For example, the Project tree has a set of six Level 2 Objectives which, in effect provide the core programmatic structure of the agency, not subject to much change over time. Within this structure, the current MTS proposes a set of defined objectives, not prioritized but in a sort of logical sequence. For example, to understand the causes of Cancer (Objective 2) it helps to start from a set of demographic and geographic epidemiological parameters. Once knowledge on the causes of cancer is developed, one can address prevention and control strategies, hence a logical sequence of activities 1 to 3, followed by relevant cross-cutting and support activities:
  - 1<sup>st</sup>, estimation of the burden of cancer,
  - 2<sup>nd</sup>, relate knowledge of carcinogenicity (which may vary with eco and socio-behavioral systems around the world) to cancer prevention and tumor classification and causes of cancer,
  - 3<sup>rd</sup>, evaluation of interventions and their implementation from efficacy to effectiveness by going from randomized trials towards observational studies, which shed light on occurrence and causes of cancer,
  - 4<sup>th</sup>, increasing the capacity for cancer research and sustaining global leadership in cancer prevention research, as attested by its historical success rates in competitive grants.<sup>8</sup>
  - 5<sup>th</sup>, Human Resources training
  - 6<sup>th</sup>, laboratory and computing services
  - 7<sup>th</sup>, biobank
  - 8<sup>th</sup>, strategic leadership
  - 9<sup>th</sup>, communication & dissemination
  - 10<sup>th</sup>, global leadership on cancer prevention.
- 24. By means of the programmatic framework structured around the 6 Level 2 and subsequent Levels, 3 and 4, Objectives, followed by corresponding Projects, the MTS provides the basis for the Proposed Biennial Programme and Budget, and areas of coverage of IARC.
- 25. It is assumed that, as Level 3 and Level 4 Objectives are derived from Level 2 Objectives, they reflect the same programmatic structure. As one moves towards the Project tree there seems to be <u>horizontal alignment</u> of Level 3, 4 Objectives with the 6 structural Level 2 Objectives

<sup>&</sup>lt;sup>7</sup> This reorganization consisted of shifting and merging of units, rather than major restructuring.

<sup>&</sup>lt;sup>8</sup> Despite recently going down (2007=35%, peeked in 2015 and 2018=20%), but with an average of 27% during this period. As the evaluation team is not privy to any benchmark on the rates of success of such competitive bidding for research grants, it is not possible to evaluate these rates.

(describing the occurrence, causes, prevention, research capacity, and leadership and coordination of cancer research). However, the evaluation team, due to time constraints, was not able to assess horizontal alignment with the defined MTS focus areas and determine if the actual **project budget proposals** are the result of level objectives sequentially aligned.<sup>9</sup>

26. According to the SC, the primary method for the evaluation of IARC's scientific and research performance and alignment with its mandate is the (five-year cycle) independent peer review commissioned by the SC of Scientific Sections and Groups. Other assessment points include the internal review (by the Director of IARC) of the application for research grant funding. In addition, research published in peer reviewed publications serves as a means to assess performance and alignment at the cutting edge. The evaluation role of the MTS is intended to provide a broader overview of the direction and progress of IARC as a whole, not at the project level. (GC/59/R6).

#### Divergent perspectives on opportunities for improved strategic alignment

- 27. The importance of bringing sharper strategic focus to the prioritization of IARC's research programme is viewed differently by various stakeholders. Some, particularly IARC staff maintained that IARC's mandate is appropriately broad, accommodating a broad agenda regarding cancer research. They further perceived that, where there are choices to be made, the MTS does point out such choices and selected areas of focus. Some underlined that the intellectual freedom that comes with this breadth serves as an incentive to attract and retain some of the world's best cancer researchers.
- 28. By contrast, other stakeholders argued that there is a need for greater discipline in IARC's prioritization processes, which they described as taking a more inverse approach than that usually employed in strategic planning. Specifically, they claimed that the MTS development process has historically been used as a validation exercise to justify continuity of the Agency's existing work programme, rather than being an opportunity to rethink its priorities in light of the evolving "state of the field" – or in a clear articulation of the Agency's comparative advantage in what they view as a "crowded field" of cancer research, particularly in light of IARC's financial sustainability challenges. As the current focus is on the preparation of the MTS for the next cycle, there are expectations that it will be a vehicle for incorporating current trends set by the Sustainable Development Goals (SDGs), WHO's 13th General Programme of Work 2019-2023 (GPW13), the strategic plan of the WHO for the next five years.<sup>10</sup> Others more broadly assessed the MTS as being risk averse and not well suited to identify emerging research trends and pertinent upcoming opportunities, or pointing out activities which should be phased out and those that should be expanded. Individuals who have participated in previous MTS processes asserted that previous plans have been heavily influenced by the predetermined research orientations and preferences of individual directors - a notion which, some added, is not necessarily an inherently negative or unimportant influence but rather one which has not always been counterbalanced by these other considerations or the involvement

<sup>&</sup>lt;sup>9</sup> Programme and Budget, 2018-2019: Guide for Preparation and Submission of Project and Budget Proposals

<sup>&</sup>lt;sup>10</sup>The "3 billion" are "the goals" associated to the 3 strategic objectives: 1) 1 billion more people achieving universal health coverage; 2) 1 billion more people protected from health emergencies; 3) 1 billion more people enjoying better health and well-being.

of other stakeholders.<sup>11</sup> (In this vein, in interviews and desk review it was noted that key WHO divisions, including the newly established Science Division, constitute natural stakeholders for inclusion in future planning processes. See Part F.) Some advocated for a bold and ambitious view of the future of IARC and suggested to not plan around funding limitation as a starting point. Others advocated for a greater effort to leverage the interaction with the WHO, especially with regard to its plans for the WHO Academy projected to be built in Lyon, as constituting an important hub for research and education in health.

- 29. Complementary to the MTS are the Scientific Council's commissioned Independent Section Reviews, another prospective exercise undertaken to help ascertain the continued alignment of the work undertaken by IARC's Sections.<sup>12</sup> Despite the considerable effort in undertaking these, only one interviewee viewed this exercise as extremely useful in helping the Sections open their vistas, explore new areas for project work and assess which areas need to be strengthened and those that merit a lower priority. Most importantly, these Reviews complement the MTS by going into the research projects and assessing their alignment with IARC's goals. At the same time, neither these reviews nor the MTS challenge on-going projects, to the point of recommending their suspension or cutting them short.
- 30. Most WHO staff interviewed were unaware of or involved in IARC's strategic planning and IARC's criteria for research prioritisation and related decision-making were not known and/or understood by the WHO staff. Some felt that a systematic and targeted involvement of WHO in IARC strategic planning and annual discussions between IARC and WHO is needed where research priorities are jointly identified, according to agreed criteria (for example: burden of disease, public health impact: biggest challenges where answers are needed).

<sup>&</sup>lt;sup>11</sup> Some of these stakeholders further add that the notion of a five-year strategic plan is particularly challenging because IARC's budget cycles operate on a two-year basis, with funding beyond the budget cycle being unpredictable and to a significant extent dependent on competitive grants. <sup>12</sup> Sections are the lead/highest organizational units of IARC.

#### **Key Findings**

- Owing to the breadth of IARC's mandate, as articulated in the Statute, and of the Medium-Term Strategy (MTS), the MTS 2016–2020 is seen to be closely aligned with the Statute in the sense that its research programme centering on surveillance, causes and prevention of cancer is *consistent* with the mandate.
- IARC has historically prioritized research on surveillance, causes and prevention of cancer and capacity building, paying special attention to low- and middle-income countries (LMICs), ranging from basic research to cancer registration to methodological approaches to data analysis. Although research on treatment has not been prioritized, IARC's research portfolio includes aspects that relate specifically to treatment (i.e. management of pre-cancerous lesions, impact of treatment on cancer survival).
- In turn, **the alignment of individual research projects to the MTS objectives is similarly high**, owing to the comprehensive nature of the Project Tree (i.e. the platform for ensuring alignment of projects to the MTS), which effectively allows each research project to be clearly located within the broad strategic areas articulated in the MTS. The projects subsumed under IARC's research programme are seen as being highly consistent with the MTS and, by extension, the mandate.
- At the same time, whereas each of these levels of IARC's strategic planning exhibits a high degree of *internal consistency*, **the need to face finite resources requires a** *strategic prioritization*. Prioritization can be further developed through the MTS process which has largely been shaped around the existing research programme in the past as opposed to the strategy driving the programme. Some stakeholders reported that where strategic prioritization has occurred, it has typically been rooted in individual directors' research orientations and preferences as opposed to a more institution-based rationale.

#### Recommendation

• To maximize its impact in the face of its resource constraints, IARC should engage in an inclusive, transparent and focused strategic prioritization process during the development of the MTS 2021-2025, within its defined emphasis on surveillance, causes and prevention of cancer, and capacity building.

- B. The collaboration between IARC and other parts of WHO to ensure clear definition of roles and effective cooperation and coordination
- 31. Despite the close relationship between IARC and WHO IARC is a specialized agency of WHO data collected in this evaluation revealed that collaboration, coordination and communication between the two have historically not been exploited to their full potential. The evaluation further identified three overarching areas of such collaboration, coordination and communication, namely efforts to: (1) avoid uncoordinated communication and miscommunication on issues of cancer hazard and cancer risk that could have negative consequences for both organizations' reputational risk (and for the understanding and use of such information in the public domain); (2) achieve greater communication exchange in areas of mutual interest, e.g., in order to maximize consistency and complementarity of operational processes such as strategic planning, and to ensure greater overall visibility of IARC through its association with WHO; and (3) positively capitalize on each other's mandates and work for the mutual benefit of both organizations and, by extension, to public health aspects of cancer prevention and control. As Part A discusses the first and third area of collaboration.
- 32. Information obtained in interviews described a small but consequential number of instances in which IARC and WHO had failed to coordinate their assessments of specific substances' cancer hazards and risks and subsequently to communicate their respective assessments in a manner consistent with each other. As a result, communication to the public represented two divergent messages from the WHO "family" on whether these substances were in fact significant carcinogens. The fallout that ensued was widely described as having damaged both organizations' reputation in addition to providing confusing guidance to the general public.
- 33. In the aftermath of these missteps the Governing Council, in its 59th Session of 16-18 May 2018, issued a document on "Coordination and Communications Mechanism between IARC and WHO at Management and Coordination Level" which discusses issues related to the coordination between these agencies and proposes standard operating procedures (SOPs) formalizing this coordination. The SOPs were adopted at the same session in resolution GC/60/R7, and specifically centered on improved interaction in two areas, namely: (a) a collaborative IARC-WHO review of the methodology for the Monograph and Handbook series (where the aforementioned cases had arisen) issued by IARC's Section on Evidence Synthesis and Classification (ESC), jointly with the WHO's Guidelines Review Committee; and (b) strengthened communication surrounding research findings surrounding cancer risks and hazards.

## Collaboration to avoid future missteps surrounding cancer hazard and cancer risk

34. In response to the issues that triggered the development of the SOPs, beginning in mid-2017, IARC and the WHO embarked on joint efforts to strengthen their coordination and communication mechanism in connection with cancer hazard identification and cancer risk assessment.

- 35. Furthermore, based on the recommendations from an external advisory group, supported by a meeting of experts from IARC and the WHO, a revision of the IARC Monographs Preamble was adopted in January 2019, thereby updating the relevant methodology.<sup>13</sup> The new methodology for Monographs is marked by an enhanced transparency, and by modernized methods for identifying, evaluating and synthesizing evidence and reaching uniform cancer hazard classifications. Expert WHO staff participated actively in this exercise. Similarly, the Handbook Working procedures were updated in 2019, also in a broadly consultative manner and including the WHO staff. These new methodologies will take full effect as of 2020.
- 36. In addition, and toward the same end, in August 2017 then Director IARC strengthened the Office of Communications by assigning to its head the function of IARC External Relations and Advocacy Officer to WHO, and defining its role in this regard, covering a specific period (September 1, 2017 to August 31<sup>st</sup>, 2018). This period was further extended by the current Director. As illustrated in the Directors report of 2017, IARC WHO collaboration is in fact taking place, e.g., in the form of assorted joint missions, attendance at meetings called by either party, and other areas.
- 37. There was general agreement among respondents that the communication between WHO and IARC had improved in recent years with regard to timeliness and frequency. At the same time, they felt, that there was still room for further improvement and even closer engagement. Interviews with pertinent IARC senior staff confirmed that IARC fully complies with the SOPs, and that risks of miscommunication regarding results of research on carcinogens have been minimized.
- 38. A few stakeholders at WHO pointed out that IARC's methodology for assessing cancer hazards and its classification scheme differed from WHO's methodologies and classifications. WHO senior staff did appear unaware of the recent updates of relevant assessment methodologies by IARC (involving WHO experts). IARC staff emphasized the complementarity of respective methodologies and highlighted that IARC's methodologies for assessing hazards have been adopted or modelled after by several relevant national institutions (including in the US).

## Collaboration for the mutually positive benefit to both organizations

- 39. In addition to stipulating the SOPs on coordination and communication surrounding cancer risks and hazards, the IARC Governing Council document GC/60/13 highlights in its Annex 2 several areas where strengthened collaboration between IARC and the WHO could benefit both organizations. These include the following areas:
  - (a) Non communicable diseases (NCDs);
  - (b) Supporting normative work by WHO;
  - (c) Global cancer statistics;
  - (d) Classification of cancer; and
  - (e) WHO Regional Offices.

<sup>&</sup>lt;sup>13</sup> More information about this process can be found on the relevant IARC website (https://monographs.iarc.fr/iarc-monographs-meetings/advisory-group-to-recommend-an-update-to-the-preamble-to-the-iarc-monographs/).

The document also calls for collaboration in the form of interaction in certain research projects, exchange of scientific information (especially in the areas of reproductive health, hepatitis, environmental and lifestyle-related cancer prevention issues, associated with, and more broadly in the interaction with the WHO regional offices, among other areas), and suggests the mutual advantage of such collaboration to both entities.

- 40. Importantly, the SOPs did not rise to the level of a rule to be "complied with" but rather constitute a set of procedures to be "followed," leaving considerable leeway for the two organization to engage in collaboration when and where they choose. (See Part A: participation in each other's strategic planning processes could help identify those areas where collaboration could be most meaningful and impactful to both organizations.) IARC's relative autonomy from WHO as a specialised agency further reinforces the voluntary nature of such collaboration, as do its accountability lines whereby: although Article VII of the Statute establishes the authority of WHO's Director-General over the Director of IARC, in practice Director IARC reports directly to the Governing Council through its Chair rather than to the WHO's Director-General (who does, however, also sit on the Governing Council, but is usually represented by a designated staff member).
- 41. Within this context, the review uncovered evidence of effective, though limited, positive voluntary collaboration between the two entities. In the area of nutrition, there was direct collaboration between IARC and the WHO-EURO on a project in nutritional surveys. More specifically, IARC developed tools to assess nutrition and diet and handed them over to the WHO EURO for actual use. Cooperation with WHO HQ in the area of eliminating cervical cancer is widely seen as successful and yielding practical direct benefits for public health systems. This includes work on vaccination schemes, screening and follow-up as well as related research in health economics. Other noteworthy cooperation examples include the classification of types of tumors. Collaboration also took place on guidelines for therapy and drugs for Diabetes and Obesity, both health conditions investigated by IARC as causes of cancer. Such collaboration was noted as taking place mostly on an individual basis between peers with shared substantive interests who know each other rather than on an institutional basis.
- 42. At country level, the WHO Country Offices often provide a crucial imprimatur that complements and facilitates IARC's work. Of note is WHO's support to IARC in screening and early detection activities, as well as cancer surveillance. At the same time, there is very close collaboration in operational, administrative, legal, financial, human resources, information technology systems, and procurement areas, both at strategic and working level between IARC Director Administration and Finance and relevant WHO counterparts, including WHO's six Regional Offices. In addition, IARC's administrative group heads participate regularly in global network meetings with their WHO counterparts.
- 43. Despite these examples, almost all stakeholders interviewed noted that collaboration between the two entities is not as broad or deep as it could be, specifically at the nexus of cancer research and public health policy. Moreover, while GC document GC/60/13 provides examples of successful collaboration, interviews by the evaluation team with IARC staff did not reveal

widespread awareness of such collaboration. The reason for this may be that the SOPs focus mainly on collaboration in connection with the Monographs and Handbooks.

44. Several respondents indicated that the terms of such collaboration need to be formalized and norms set to regulate them. In support of such norms, an effort should be undertaken to identify and disseminate information about the relevant counterparts (units and staff) in the WHO of the different Sections and Groups of IARC. Furthermore, in support of these norms some felt that joint meetings/retreats should be arranged for the relevant counterparts and respective units in IARC to meet and learn of their respective work scopes. This should facilitate further collaboration going forward.

#### Key Findings

- Despite IARC's status as a specialised agency of WHO, collaboration, coordination and communication between the two entities have historically not been exploited to their full potential. The most frequently cited instance of interaction revolves around reactive crisis communications resulting from past instances of poorly coordinated communication on specific cancer hazards and risk- and subsequent effort to avoid such crises in the future.
- In response to these cases, **SOPs have been developed to align communication** so as to avoid future discrepancies and miscommunication. These SOPs are currently being used, although they have not been tested for effectiveness as no recent publications with diverging results have been released by the two organizations.
- IARC's methodologies for the assessment and classification of cancer hazards (Monographs) and the procedure for writing IARC Handbooks were updated in early 2019 through a consultative process involving a broad range of stakeholders, including WHO staff.
- In the same Governing Council-approved document launching these SOPs, IARC and WHO were called upon to more broadly strengthen collaboration in ways that both entities could potentially benefit. There are noteworthy individual examples of this more positive form of collaboration. Such collaborations have largely been based on pre-existing inter-personal relationships, however, rather than on a systematic approach to identifying and seizing on opportunities to work together. Specifically, **opportunities for collaboration at the nexus of cancer research and public health communications have not been fully exploited** e.g., translating the state of research on cancer hazards, risks, and preventive measures into policy recommendation and communications. (*This gap potentially has ramifications for strategic planning processes, discussed in Part A, and for communications, discussed in Part F.*)
- The definition of the Liaison Officer role and associated resources for the Communications Office represents a step forward toward greater collaboration between the two entities.
- At the same time, there are capacity constraints for such collaboration on WHO's part, with limited staff members working on cancer issues full time at headquarters.
- IARC, working with WHO, has made steps to synchronize the IARC Governing Council and WHO Executive Board meetings, that would thus enable participation of IARC and WHO management and staff in each other's governing body meetings.

#### Recommendations

- As WHO's newly established Science Division shapes its research agenda for the Organization, Director IARC, working with the Science Division through WHO's Chief Scientist and engaging the support of WHO's leadership, should:
  - ensure the inclusion of WHO, through its Chief Scientist, in the MTS 2021-2025 development process;
  - articulate and implement a joint strategy for improving communication between IARC and WHO, with a view to achieving gains in efficiency, transparency and effectiveness, as well as to further pre-empting and reconciling situations where IARC and WHO might otherwise have divergent public statements on a given topic;
  - identify and pursue relevant, concrete opportunities for bringing the added value of IARC's substantial scientific expertise in cancer prevention and control to bear on WHO's research agenda; and
  - seek to produce, together with WHO, a range of relevant co-owned and co-authored technical documents that involve a review of scientific knowledge and policy or clinical recommendations.
- IARC, working with WHO, should ensure that efforts currently underway to synchronize the IARC Governing Council and the WHO Executive Board meetings are realized, thus enabling participation of IARC and WHO management and staff in each other's governing body meetings.

- C. Contribution of multi-disciplinary research to IARC's strategy in cancer research, including the balance of laboratory equipment in-house and accessed through external collaboration
- 45. A multi-disciplinary approach to cancer research requires close collaboration between the scientific areas involved in and/or contributing to a research project. The vast majority of IARC's research work is conducted in the framework of projects which involve several external collaborating partners, each contributing specific scientific expertise, resources and capacities. Most respondents agree that the multi-disciplinary approach is an inherent and necessary feature of any modern and complex area of cancer research. Some feel that the multi-disciplinary capabilities of IARC are one of its comparative advantages, as IARC is uniquely placed to access a vast array of disciplines across borders and without the element of competition. At the same time, several staff expressed the view that there are some internal barriers to closer collaboration within IARC, which prevent for example the joint management of large cross-cutting research projects. Some of these relate to competition for funding from similar sources, others are related to a lack of awareness of work conducted within other Sections at IARC. Most agreed that it is important to promote a collaborative work culture and to discourage and break up the silo/stove pipe work flows.
- 46. IARC implements such a multi-disciplinary approach to cancer research, whenever it is appropriate. As a result, IARC's multi-disciplinary research projects have generated improved knowledge and understanding of cancer etiology and mechanisms of carcinogenesis, leading to policy recommendations for the prevention and early detection of cancer at a public health level, evidenced by relevant publications. Multi-disciplinary refers to IARC's integrated use of: (a) its in-house capacities and expertise in cancer epidemiology, etiology (infections; nutrition and metabolism; genetics), molecular carcinogenesis, epigenetics, molecular pathology, and others, supported by such research tools as biostatistics, bioinformatics, biomarkers, and supported by several laboratory "platforms"; and (b) external and complementary expertise contributed through collaborating partners (mostly research institutes) from IARC's Participating States as well as from other countries. A few respondents pointed out that IARC's various training programmes reflect this approach to a multiplicity of disciplines, too; for example, through course content which cuts across areas of expertise as well as training curricula for visiting researchers and fellows that lead a trainee through several research disciplines. Several interviewees mentioned that there is no longer a standard or traditional set of disciplines in cancer research; new subject matters emerge, evolve further and potentially inspiring yet other disciplines. Consequently, IARC needs to be flexible and open to some areas that were previously not considered for inclusion, such as health economics.
- 47. A clear majority among respondents from the Governing and Scientific Councils expressed that they were very or somewhat satisfied with the contribution of multi-disciplinary research to IARC's strategy. To further strengthen IARC's multi-disciplinary approach, a large number of respondents (GC and SC) suggested that IARC identifies opportunities to share infrastructure resources with other research institutes, further enhances collaboration with relevant entities and embarks on strongly prioritizing its activities. IARC respondents considered strong prioritization, strengthened internal communication and coordination, and a

more streamlined administration as important areas for improvement in the context of multidisciplinary work.

- 48. The balance between IARC's use of in-house laboratory capacities and similar external capacities (accessed through research collaboration, outsourcing or other arrangements) appears to depend on the specific research subject matter, the design of the research project, the specific capacities and the expertise of the collaborators involved, the timeframe required for outsourcing and on the pertinent costs. The necessity to have in-house laboratory capacities is widely recognized among IARC stakeholders; the need for specific capacities including their relevant maintenance and upgrading has been reviewed in connection to selected capacities ("platforms"), mentioned hereunder. The strong need for state-of-the-art laboratory capacities was confirmed by most interviewees. At the same time, some of them suggested that there is room for better prioritization of research laboratory needs and that IARC could outsource more of its research work.
- 49. Genomic applications are an important component of many IARC studies. An analytical resource shared across IARC for research purposes is the Genetics Platform<sup>14</sup>, which supports genomic-related research projects. The platform consists of the genomic related equipment, technical and bioinformatics applications as well as relevant scientific expertise in laboratory methods, pathology and bioinformatics. The platform makes genomic techniques accessible to IARC scientific groups. When looking into the platform capacities, the most recent Scientific Review Panel thought that additional in-house informatics was needed, yet it also raised the issue of ensuring the platforms long-term sustainability, including continued investment in equipment and its maintenance.<sup>15</sup>
- 50. The Scientific Review of Nutrition and Metabolics Section activities in 2018 considered the IARC's Immunoassay and MSP Platform "a very good investment in infrastructure for (biomarker related) activities, especially instrumentation for metabolomics"<sup>16</sup> and recommended that the Group follow "their plans to extend the annotation of the metabolomics database and develop the associated bioinformatics for handling the high-dimensional data"<sup>17</sup>.
- 51. Bioinformatics is an important emerging tool supporting cancer research that cuts across several disciplines such as genomics, genetics and metabolomics at IARC. Recognizing the potential contribution of bioinformatics to cancer research, the Scientific Council adopted<sup>18</sup> IARC's Strategy and Plans for Bioinformatics in 2017, which entailed the integration of bioinformatics capacities into the relevant research groups while ensuring access to this resource and information sharing across the whole organization. Similarly, capacities for biostatistics and bioinformatics are attached to research groups while sharing lessons learned and information in a coordinated manner.

<sup>&</sup>lt;sup>14</sup> IARC Genetics Platform: GSP Operational Model 12062015

<sup>&</sup>lt;sup>15</sup> Scientific Council, Scientific Report GEN Review, SC/52/WP5, Page 22

<sup>&</sup>lt;sup>16</sup> Scientific Council Scientific Report NME Review, SC/54/WP9, Page 22

<sup>&</sup>lt;sup>17</sup> Scientific Council Scientific Report NME Review, SC/54/WP9, Page 8

<sup>&</sup>lt;sup>18</sup> SC/53/8 Fifty-third Session 02/12/2016 Lyon, 25–27 January 2017

#### **Key Findings**

The evaluation of multi-disciplinarity seemed to pertain largely to laboratory versus non-laboratory activities, and particularly the balance of using in-house laboratory equipment/capacities versus accessing such capacities through external collaboration. The surveys and interviews focused on other aspects of multi-disciplinarity as well, based on consultations undertaken during the inception phase. Therefore, in terms of the balance of laboratory equipment in-house versus external capacities, additional questions were asked during the Advisory Group's final meeting. This additional information provided the input for the key finding noted below. The first three bullets focus on laboratory equipment, the next three focus on the issue of multi-disciplinarity, and the last two focus on internal collaborations across IARC units.

#### Laboratory equipment

- **IARC stakeholders recognize a need for in-house laboratory capacities** that are in keeping with IARC's core mission areas, particularly in the areas of pilot studies, quality control and confirmation, and emerging areas of research needs.
- IARC has unique needs related to laboratory capacities for studies conducted in LMICs, including opportunities for providing training capabilities for students/scientists visiting from LMICs.
- IARC has an established process for avoiding redundancy with other scientific efforts (national or otherwise), and plans to maintain this process.

## Multi-disciplinarity

- IARC implements a multi-disciplinary approach to cancer research, whenever appropriate. The vast majority of IARC's research is conducted in the framework of research projects involving several external collaborating partners, each contributing specific scientific expertise, resources and capacities.
- The multi-disciplinary character is manifest through IARC's standard approach of integrating relevant in-house capacities and expertise with complementary external expertise and capacities contributed through collaborating partners.
- In cancer research there is no standard set of disciplines: new subject matters emerge and evolve further, inspiring yet other disciplines. IARC has maintained some flexibility to adapt quickly to tackle new research domains, e.g. the inclusion of health economics among its capabilities. The classic disciplines supporting IARC's research are constantly being supplemented by new ones as the evolution of research indicates the need.

#### Internal collaborations across IARC units

- While there is strong cooperation among several Research Sections within IARC, truly integrated and coordinated projects are not facilitated when Sections are competing for funding from the same external source.
- There is significant room to further strengthen the collaboration between Sections within IARC with a view to facilitate prioritization, to optimize the use of common resources and to ensure the quick translation of basic research results towards implementation research.

#### Recommendations

- The move to the Nouveau Centre provides an opportunity for IARC to undertake a strategic process to optimize planning for the future and consider which are the core in-house laboratory capacities to incorporate in the new building and which are best obtained through collaborations with external laboratories to maximize efficiencies. Toward this end, IARC should:
  - develop a more detailed description of the process it has been using to ensure efficiencies in decisions on core in-house laboratory capacities versus collaborative laboratory capacities and share this information with the Scientific Council and the Governing Council, thus providing examples of how this process has been implemented with some specific projects; and
  - use the MTS 2021-2025 consultation process to explicitly include an in-depth discussion of this key aspect of IARC's work, based on a review of relevant evidence and data, resulting in a clear strategy for balancing its internal and external laboratory facilities to be implemented moving forward.
- As bioinformatics needs are an increasingly important component of laboratory capacity, IARC should regularly update the Scientific Council and Governing Council on the computational and data storage needs for bioinformatics into the future.
- Given its financial constraints, IARC should intensify its efforts to obtain additional laboratory, bioinformatics, and other disciplinary expertise through collaboration, Visiting Scientists, and secondments from Participating States and other partners. The results of these efforts should be incorporated into the aforementioned for balancing its internal and external laboratory facilities or in a separate strategy to be implemented moving forward.

## D. Role and infrastructure for the biobank in IARC's research strategy

- 52. The proper storage and accessibility of human biological specimens is essential for the study of the causes and prevention of cancer. In this vein, the objective and purpose of IARC's biobank<sup>19</sup> is to support research activities across the agency, including by being a reference point for a large number of studies.
- 53. Currently, it stores almost 7 million samples from more than 50 countries, derived from international collaborative population-based studies, including 3.5 million from the European Prospective Investigation into Cancer and Nutrition Study (EPIC) collection. The biobank also acts as custodian for collections from research consortia and networks from LMICs.
- 54. The biobank infrastructure comprises: a storage facility with liquid nitrogen tanks and freezers, a laboratory information management system (specific software and data warehouse), a DNA and RNA extraction platform for analytical purposes as well as support structures for shipping and handling and a nitrogen storage tank.
- 55. This evaluation examined the role and infrastructure of the biobank in IARC's research strategy, focusing on two main areas in keeping with the key issued gleaned during the inception phase. These included: (a) the overall relevance, importance and utility of the biobank to IARC's research strategy, and (b) the extent to which IARC has explored various options for ensuring that the biobank remains fit-for-purpose and as cost-efficient as possible in comparison to potential alternative models moving forward. As an independent, objective assessment of these areas, the evaluation did not delve into the political considerations of whether the biobank should exist in the first instance. That said, Governing Council and Scientific Council members' perspectives on this issue were explored in the online survey.

## Role and infrastructure of the biobank in IARC's research strategy

56. The biobank is contributing to and supporting the research work of the following IARC Sections: Genetics, Nutrition and Metabolism, Early Detection and Prevention, Mechanisms of Carcinogenesis, Evidence Synthesis and Classification and Infections. The unanimous view of interviewees was that biobank services, i.e. access to specimen and relevant pre-analytical services, are a necessity for their research work in these Sections. Access to biospecimens are required for approximately 50% of IARC's research projects in the above Sections<sup>20</sup>. IARC respondents highlighted the biobank's support to IARC's research work with a high rate (70%) thereby underlining the perception of the crucial and integral role of the biobank for the implementation of IARC's work. Respondents further underlined the global impact of IARC's biobank activities with a high rate (69%) noting its unique features and the high quality and

<sup>&</sup>lt;sup>19</sup> biobanks are "...structured resources that can be used for the purpose of genetic research and which include: (a) human biological materials and/or information generated from the analysis of the same; and (b) extensive associated information... established, governed, managed, operated, accessed, used and discontinued in accordance with applicable legal frameworks and ethical principles." per ISO 20387

<sup>&</sup>lt;sup>20</sup> Estimate provided by Head of the Biobank Group.

accessibility of its samples. At the same time, they identified a strengthened management of the biobank services as one key area for improvement.

- 57. In addition to access, pre-analytical services for samples are provided, such as DNA and RNA extraction and data retrieval from annotated (characterized) samples. Access to biospecimen for research purposes is also provided to external organizations/requesters (i.e. independent of IARC research projects), always on a cost-recovery basis. Granting such requests requires a successful independent ethical review as well as the conclusion of a so-called Material Transfer Agreement.
- 58. Since 2013, in total, the biobank supported 388 research projects (internal and external) and since 2012 over 1 million samples were moved/accessed. In 2018 alone, about 200,000 new samples were imported into the biobank and 50,000 samples were accessed for internal or external collaborations. Stringent quality control measures are in place to ensure the high quality of samples. The biobank participates in International Proficiency Testing schemes, scoring highly, and carries adequate back-up facilities.
- 59. The collection of unique samples, securely stored by an impartial entity and accessible to researchers worldwide was noted by many interviewees as integral to IARC's research and aligned with its mandate. With regard to the role and importance of the biobank for the implementation of IARC's work, 70% of IARC respondents identified "to support IARC's research work". Among the WHO staff, respondents were somewhat aware of IARC's biobank facilities but none of them felt they had sufficient insight or information to advance views on the specific role and infrastructure of the facility nor on the sustainability of its operational model. A few respondents with slightly enhanced awareness referred to IARC's biobank as an important global resource.
- 60. Half the GC respondents were very or somewhat satisfied with the role and infrastructure of the biobank in IARC's research strategy. Among the SC respondents 65% were very or somewhat satisfied with the role and infrastructure for biobank in IARC's research strategy. Both GC and SC respondents identified a more focused/prioritized usage as an area for improvement, followed by ensuring sustainability, and a clear positioning of the biobank and ensuring cost effectiveness.
- 61. With regard to IARC's role as a neutral custodian of bio-specimens, it was pointed out during interviews that the security and integrity of the current set of unique bio-specimens entrusted to IARC could not be guaranteed during transport to and storage at (hosted) third party's premises. In this situation, IARC would remain responsible and accountable for security and integrity of the specimens but without effective control. A risk analysis and feasibility study in relation to transferring the biobank to a third party has not been conducted. There was the unanimous view among IARC staff that IARC's biobank capacities cannot be outsourced to another biobank because of the costs, risks and liabilities involved. Interviewees pointed out that the transport and hosting of specimens to biobanks with unknown security standards, would render this option unviable and/or unattractive.

#### Efforts to ensure the biobank's sustainability

- 62. Although the evaluation did not delve into the political dimensions of the biobank, information obtained during the inception phase revealed that there are diverging perspectives on whether the biobank should exist as such, and if so in what form. Toward this end, the evaluation did assess what if any approaches IARC has explored to ensure the financial and operational sustainability of the biobank.
- 63. Interviews revealed that IARC is well aware of the sustainability issues surrounding biobank facilities, including expenditures in connection with the biobanks operation and maintenance. Accordingly, efforts are underway within IARC to identify opportunities for additional cost-recovery schemes, and rational use of storage space. Relevant concepts and policies are under development. A cost/benefit analyses of the current biobank operation has not been conducted.
- 64. Globally, there is an increased demand by researchers for the provision of data/analytical results instead of access to physical samples. In anticipation of such demands, IARC has formulated a draft policy to enable the efficient provision of such services in connection with the biobank, including relevant cost-recovery schemes.
- 65. The majority of the stakeholders were aware that the costs related to biobank services, including for operation, maintenance and replacement, are an important issue for IARC and that a sustainable operational model is required. Interviewees clarified that in general biobanks produce results in the form of "return of investment" after about 8-10 years. Yet, after 4 years of operation, a secondary round of investment is normally required, often for the replacement of freezers. This regular occurrence is often perceived (wrongly so) as an indicator for a biobank's non-sustainability. Among those IARC staff members aware of the financial issues surrounding the biobank, a majority were satisfied with efforts to ensure its sustainability (64%); however, this percentage only represents the proportion of those aware of the issues (i.e. 54%), with a similar proportion (46%) reporting that they were not aware of these issues. Among SC respondents, views on IARC's efforts made to ensure the biobank's sustainability were evenly shared between being somewhat satisfied and somewhat dissatisfied. On the same issue, among GC respondents, just over half (55%) indicated being somewhat or very dissatisfied with the current efforts.
- 66. IARC respondents identified strengthened management of the biobank services with a rate of 54% as a key area for improvement with regard to the future of the biobank, followed by improvements in connection with research work. Answering the same question, GC respondents identified focused usage (including on LMIC needs) with a rate of 53%, followed by the need for sustainability and clear positioning, while SC respondents identified prioritized usage (including strengthened usage for LMIC) with a rate of 56%, followed by the need for sustainability and cost effectiveness.
- 67. There were mixed views on replacing current liquid nitrogen tanks with automated models. Respondents in favour of the automation saw increased efficiencies in handling samples (reducing workload) and better protection of sample integrity (shortened exposure time). Others thought that these small advantages do not warrant such an investment. Furthermore, several respondents argued that the current size and structure of IARC's biobank should not

be expanded further. Instead a stricter prioritization of activities and the consequent implementation of cost-recovery schemes (including potentially for internal research work) should be pursued. In addition, some respondents thought that outsourcing of DNA extraction is a feasible option to be considered.

68. A respondent explained that mobilizing extra-budgetary resources for IARC's biobank has proven difficult. Efforts to seek European Commission funding, for example, failed because of IARC's status as international organization.

#### **Key Findings**

- IARC's biobank is essential for research in multiple IARC Sections, notably Genetics, Nutrition and Metabolism, Early Detection and Prevention, Mechanisms of Carcinogenesis, Evidence Synthesis and Classification, and Infections.
- **IARC's biobank is viewed as an international resource** and IARC can act as a neutral custodian of bio-specimens entrusted to a neutral space.
- Human studies are often substantially enhanced if blood or tissues can be obtained and stored; the opportunity-costs of not undertaking such collections are large
- There is strong staff sentiment that IARC's biobank capacities and services cannot be transferred/outsourced or relocated, but this sentiment should be re-examined periodically.
- The placement of the biobank under the IARC/WHO umbrella imposes restrictions that might not apply to national or academic biobanks, particularly with respect to relations with industry.
- Access to bio-specimens for research is provided to external organizations/requestors, although the main focus is internal and collaborative research, particularly the EPIC cohort.
- Cost-recovery charges appear to be lower than in many biobanks.
- The cost-effectiveness of the biobank's operational model has not yet been assessed in great detail, yet such assessment could provide a basis for further decision-making on investments.

#### **Recommendations:**

- IARC's biobank is essential to fulfil its global role in international study coordination and science contributions. In order to enhance its capacity, IARC should:
  - o undertake regular assessments of the value of keeping older, legacy samples;
  - ensure that the proportion of IARC biobank samples/usage that is represented by the EPIC study is assessed with respect to value for money to IARC;
  - conduct an assessment of whether charge-back costs are compatible with similar biobanks internationally;
  - enhance online transparency of IARC biobank sample sets and access regulations, as a matter of priority;
  - o streamline the process for engaging in public/private collaborations using the biobank;
  - consider efficiency trade-offs for the location of the biobank on site or at remote location; and
  - analyze policy constraints and sample ownership changes that could facilitate largescale analysis of specimens by commercial companies.
- IARC should assess whether its collection of biologic samples is optimal in view of IARC's global mission. Toward this end:
  - The balance between developing new biobank resources and sustaining the existing biobank should continue to be carefully considered; and
  - IARC should exercise its convening power to increase access to the biobank and data across consortia in an equitable manner.

- E. Mechanisms to ensure the financial sustainability of IARC's research including the laboratory research and biobank
- 69. After many years when assessed contributions provided a reliable financial framework, according to which IARC's biennial program and budget were planned, approved (after discussions) and implemented, IARC's financial situation is currently marked by relative volatility with regard to the assessed contributions of its Participating States. Additional research funding needs were adequately addressed through competitive research grants and contributions, but this situation has also changed in recent years whereby IARC faces a more competitive research environment with an increased number of contenders in the cancer research arena.
- 70. Most respondents saw IARC's funding sustainability as a serious challenge, while a few expressed the belief that IARC is actually doing well with regard to obtaining competitive research funds. Several respondents pointed out that the excessive reliance on competitive research funding may influence the selection of research priorities.
- 71. WHO interviewees shared a general impression that IARC's funding situation was not very positive; however, very few had a more detailed understanding or knowledge about IARC's financial sustainability and funding sources. Among the GC respondents, around two-thirds were somewhat or very satisfied with the adequacy of IARC's funding situation. Furthermore, around two-thirds also see the funding situation of research projects through research grants as somewhat or very satisfying while a third (33%) were somewhat dissatisfied. A different perspective was offered by respondents from the SC, of whom only about a third (36%) were very or somewhat or satisfied with IARC's financial situation, while the rest were somewhat or very dissatisfied.
- 72. Seventy percent of IARC staff was somewhat or very dissatisfied with IARC's funding situation while the financing of research projects through grants was deemed somewhat adequate by half the respondents. The funding predictability is seen by a majority (> 65%) as somewhat or very dissatisfying. Most respondents suggested that IARC should expand its funding sources, for example by attracting new Participating States. Some respondents identified the need for IARC to address particular requirements of Participating States and to meet their expectations, in order to maintain the current membership and attract new Participating States. Some interviewees suggested reaching out to China, Saudi Arabia, the Gulf States, and selected Central Asian as well as to Eastern European countries, potentially with the support of the WHO.
- 73. Increasing cost-effectiveness internally was mentioned with a significant frequency. A few respondents suggested that the broad scope of IARC's work with too many activities and competing priorities adds strain on IARC's resources. Strengthened prioritization efforts were suggested by GC respondents as a key measure to address financial sustainability issues.

- 74. With respect to IARC's Regular Budget, from 2010–2011 onwards overall IARC staff costs have increased by €.75 million, a 35% rise<sup>21</sup> attributable to increases in statutory staff costs and to costs resulting from programmatic and organizational changes. Over the same period, the Governing Council adopted the approach of zero nominal growth in assessed contributions from Participating States. At the same time, in order to offset cost increases, the Governing Council agreed to increased biennial budgets through assessed contributions from new IARC Participating States as well as during 2012-2017 through the use of the Governing Council Special Fund. IARC's approved regular budget for 2020–2021 amounts to €44 149 793 and is funded solely from assessed contributions.<sup>22</sup>
- 75. Table 2 shows the distribution of IARC's regular budget 2020–2021 across "level 2 Objectives" of IARC's project tree. This distribution reflects the prioritization among these objectives and the respective needs for regular budget resources. It is noted that the distribution pattern is similar to that of the previous biennium.

	2018-2019		2020-2021	
Level 2 Objectives	(in Euros)	%	(in Euros)	%
Describe the occurrence of cancer	3 507 393	7.94	3 633 223	8.23
Understand the causes of cancer	11 719 106	26.54	11 972 571	27.12
Evaluate and implement cancer prevention and control strategies	4 317 788	9.78	4 153 150	9.41
Increase the capacity for cancer research	10 950 537	24.80	10 103 795	22.89
Provide strategic leadership and enhance the impact of the Agency's contribution to global cancer research	4 799 948	10.87	5 006 803	11.34
Enable and support the efficient conduct and coordination of research	8 855 021	20.06	9 280 251	21.02
TOTAL	44 149 793	100.00	44 149 793	100.00

Table 2 – IARC approved regular biennial budget, per programmatic priority

- 76. To further offset statutory staff cost increases, IARC's non-staff budget component has been reduced since 2010. The non-staff component in 2020-2021 is lower in absolute terms than in 2010–2011. The regular budget allocated to general management and administrative services remained stable at 20-21% over the same period.
- 77. With respect to extra-budgetary resources, the agency has financed an increasing number of staff posts (mostly in administration, and communication) from extra-budgetary sources in order to implement core programmatic activities<sup>23</sup> and provide related support. More specifically, such posts have been financed from Programme Support Costs generated from

<sup>&</sup>lt;sup>21</sup> Average staff cost was increased by 2-4 % per biennium

<sup>&</sup>lt;sup>22</sup> Turkey has suspended its membership and its contribution has been excluded from the 2020-2021 budget

<sup>&</sup>lt;sup>23</sup> Key performance indicators for programmatic delivery appear in the annual Director's Report to the GC and include: (a) publications and revenues from their sales, (b) visitors to IARCs website, (c) most popular downloads, (d) extra-budgetary funding and expenditures, (e) education and training events and attendance, (f) fellowships, meetings at IARC HQ, and collaboration activities with other entities.

overheads on research grants and direct contributions, from the Governing Council Special Fund (generated from sales of publications), or from unbudgeted assessments from new Participating States. The Agency has secured additional voluntary contributions to complement regular budget funds, particularly to finance necessary human resources for research purposes. Specifically, since 2014, the Agency mobilized approximately €52.2 million of extra-budgetary contributions (see annual breakdown in the below table), many of which are multi-year grants/contributions obtained through competitive research funding efforts. Table 3 provides an overview of extra-budgetary resources from 2014 to 2018.

 Table 3 – Overview of extra-budgetary resources mobilized based on signed contribution agreements (in million euros)

Year	2014	2015	2016	2017	2018	Total
Extra-budgetary Resources mobilized	4.18	16.72	10.24	11.86	9.18	52.18

- 78. The mobilization of these resources<sup>24</sup> reflect the continued need for additional research funding at IARC as well as the effort and investment by the agency's scientists in competing for research funding. The average success rate for competitive grant applications is 27% over the 2007-2018 period.
- 79. Extra-budgetary resources are estimated to increase by 2.23% throughout 2020–2021 (compared to 2018-2019), as shown in Table 4 below. The significant increase under objective 6 "Enable and support the efficient conduct and coordination of research" only partially reflects the (thus far unmet) needs for funding of IARC's *Nouveau Centre* project.

Table 4 – IARC estimated	extra-budgetary	resources, per	r programmatic p	riority (in euros)

Level 2 Objectives	2018-2019	%	2020-2021	%
		distribution	(in Euros)	distribution
Describe the occurrence of cancer	1 548 154	9.38	2 321 184	13.76
Understand the causes of cancer	5 934 660	35.96	5 021 643	29.77
Evaluate and implement cancer prevention	3 823 809	23.17	2 989 181	17.72
and control strategies				
Increase the capacity for cancer research	1 385 541	8.40	1 473 099	8.73
Provide strategic leadership and enhance	998 669	6.05	874 935	5.19
the impact of the Agency's contribution to				
global cancer research				
Enable and support the efficient conduct	2 812 288	17.04	4 190 870	24.84
and coordination of research				
TOTAL	16 503 121	100.00	16 870 912	100.00
Increase				2.23%

<sup>&</sup>lt;sup>24</sup> The US with a total of \$3.88 Mill was the leading country contracting research projects with IARC, followed by France with \$2.55 Mill, UK with \$0.886 Mill, Belgium with \$0.780 Mill, Denmark with \$0.281 Mill, and Germany with \$0.274 Mill.

- 80. In response to this situation, IARC formulated a Resource Mobilization Strategy in 2015 based on its then funding structure. Four strategic priorities for resource mobilization were identified: increase assessed contributions; enlarge direct and flexible funding; widen the funding base and strengthen competitive grants; and explore innovative resource mobilization and fund-raising campaigns, with a particular emphasis on the Nouveau Centre. IARC also strengthened its in-house resource mobilization capacities, including through the recruitment of relevant experts. This direction is broadly supported by IARC staff. A few respondents at IARC expressed the opinion that current resource intensive efforts to "chase money" were not a sustainable practice. Both, GC and SC respondents suggested accelerated resource mobilization efforts in order to strengthen the financial sustainability of IARC and to redress the situation.
- 81. IARC's resource mobilization towards non-traditional donors has commenced. So far however, only smaller contributions have been received. Current efforts focus on building a reliable and substantial funding stream from such sources. Outreach to and engagement with the private sector was seen by several interviewees as one new path to attract additional funding. All of them pointed out at the same time that relevant rules and regulations (such as FENSA) should be strictly adhered to in order not to jeopardize IARC reputation and integrity. Funding arrangements with the pharmaceutical industry were mostly considered as very risky for the Agency. Others saw reaching out to major private donors, foundations and philanthropic entities (such as Bill & Melinda Gates, Clinton, Bloomberg and other Foundations) as a way forward to obtain more funding.
- 82. A few IARC interviewees pointed out that IARC needs to clearly articulate the public health impact of its work, the relation of research outcomes to the SDGs and the economic case for prevention (especially in LMICs) in order to qualify for and be considered for funding from major development aid agencies and international finance institutions (World Bank, Asian Development Bank, African Development Bank, Inter-American Development Bank). In a similar vein, some WHO interviewees suggested that resource needs for cancer research were not well communicated and suggested that relevant funding needs could be presented as part of a "cancer package" from research to implementation, and involving WHO.
- 83. The Resource Mobilization Strategy underlines the importance of adequate outreach, marketing and communication capacities in connection with resource mobilization activities. While IARC's Communication Strategy (2018) clearly articulates its support to IARC's resource mobilization activities, the envisioned contribution is focusing on the provision of traditional communication products (brochures, videos, photographs and illustrations) rather than on the much-needed production of content in support of marketing and outreach for resource mobilization. Many IARC respondents underlined the importance of especially supporting new fundraising efforts by an effective and modern outreach and marketing campaign, using social media and other tools. In addition, both GC and SC respondents recommended primarily enhanced communication outreach and promotional activities to achieve a higher visibility.

84. During the in-person Advisory Group meeting, additional details of biobank charges and the charge back for sample acquisition were reviewed. The overall estimates for laboratory research within IARC were also presented. Variable estimates of costs for processing and retrieval of samples for the biobank indicated that more transparent approaches could better capture the costs of processing samples (See Part D).

#### **Key Findings**

- **IARC's finances comprise 70% assessed contributions**, which have provided a reliable financial framework to date, on which IARC has based its biennial programme and budget. Additional research funding has been sourced from competitive research grants and direct funding.
- IARC's finances are scarce for a research institution of its mandate and this is expected to continue and indeed worsen in the immediate short-term. A large amount of funding is still required for the Nouveau Centre project and these funds need to be available in one biennium preceding the move viz. 2021–22, adding further stress to the already-strained financial framework. The suspension of Turkey's IARC membership has led to further financial problems. IARC will experience a gap between its budget and funding of almost 1.5 million Euros in coming biennia.
- Budget constraints dictate a constant balancing between research priorities based on a) the Agency's longer-term objectives and b) projects inspired by funding opportunities (donor driven). Current guidance and reference documents (based on the MTS 2016-2020 and the Project Tree) are perceived as not facilitating or guiding the prioritizing or de-prioritizing of research areas, however (see Part A above).
- Potential opportunities to mobilize extrabudgetary resources from new, non-traditional donors (the private sector) have not yet been actively pursued.
- The views of the sustainability of IARC's financial situation vary significantly among different stakeholder groups.
- Scientific staff at IARC (as in other research institutions worldwide) might be dedicating an inordinate amount of time to pursuing grant resources at the expense of time spent on their research tasks.
- The recent appointment of a dedicated P5-level resource mobilization officer represents a significant step forward in addressing some of the Agency's financial challenges.

#### Recommendations

- In order to ensure the future financial sustainability of its research, and beginning with its MTS 2021-2025 process and the ensuing budgeting, communication and resource mobilization work, IARC should:
  - identify core priorities and core staff and fund these through the 70% assessed contributions, with additional activities and costs also being prioritized and paid from the 30% voluntary contributions;
  - o identify efficiency gains, e.g. negotiate more flexible contracts for staff on external grants;
  - o continue to develop a fit-for-purpose, cost-efficient Nouveau Centre;
  - intensify efforts to ensure that programme support costs related to external grants are maximally covered, i.e. not subsidized by regular budget;
  - strengthen efforts to find (recruit) new Participating states, including by showing them the clear added-value for membership of IARC as well as their existing membership of WHO;
  - continue efforts to improve and professionalize its fundraising strategies, including more effective communication of IARC's successful research and capacity-building work as a means of showcasing its value to prospective donors;
  - o explore the possibility for naming rights and endowments by philanthropists;
  - articulate the economic case for the public health impact of IARC's work including for capacity building in LMICs so that IARC may qualify for funding from major development aid agencies and international finance institutions;
  - establish a mechanism to advise the Director on IARC's future business model and its financial sustainability, either by convening a group of experts, or by appointing a professional external consulting partner;
  - IARC's comparative advantage and value proposition should be thoughtfully discussed and clearly articulated in the MTS 2021-2025 development process, then used as the basis for developing a communications strategy (and associated communications plan) aimed at showcasing the Agency's unique contributions to cancer prevention and control as a means of harnessing its full potential.

## F. Approaches to maximize the value and impact of IARC's work

- 85. In the present evaluation, five main approaches were identified that have sought to maximize, or have the potential to further maximize, the value and impact of IARC's work. These include:
  - **engaging in strategic planning processes** through which IARC focuses its finite resources on those lines of work that are most consistent with its mandate and that best seize on its comparative advantage (value proposition), rather than inversely retrofitting such plans to its existing research programme, unnecessarily duplicating what others are doing, or treading into territory where it lacks comparative advantage and where others are better positioned;
  - **communicating its overall identity and its specific work**, the former consisting of general external communications to grow and maintain visibility by clearly conveying its comparative advantage and value proposition, and the latter consisting of strategic dissemination of its specific publications and other outputs;
  - **collaborating with the WHO**, both to capitalize generally on the global recognition that the WHO association lends and to build on the results of its cancer research by bringing these to bear on the normative guidance, advocacy, and communications work of the WHO so as to translate the concrete ramifications of this research into public health policy guidance;
  - **collaborating with other cancer research institutions globally**, including through multidisciplinary research, through which it achieves greater exposure through a wider network of institutions, both generally and through the dissemination of specific joint research work; and
  - **undertaking resource mobilization efforts** to grow the resource base that enables it to achieve greater impact through its work.
- 86. As the previous parts of this report illustrate, each of these approaches has been marked both by noteworthy successes and by outstanding gaps that would likely benefit from greater attention. Some of the ways in which IARC has sought to maximize its impact include, for example:
  - a) producing an MTS in line with IARC's mandate;
  - b) generating and managing a complex programmatic and organizational structure that defines operationally the action of IARC;
  - c) striving to develop a policy of collaboration with the WHO, at least in critical interface areas in a way that it builds its value and image; and
  - d) developing the ability to generate substantial complementary funding by successfully applying for grant funds.

Conversely, some of the outstanding gaps highlighted include, for example:

- a) communicating its comparative advantage and accomplishments in a way that positively enhances its brand, its visibility and its resources;
- b) seizing on potential opportunities for greater positive collaboration with the WHO;
- c) reaching beyond its traditional sources of funding or significantly expand membership in the Governing Council to a level that can generate a satisfactory level of predictable revenue; and
- d) definitively resolving the uncertainties surrounding the funding of its technical infrastructure, mainly the biobank.

In these ways, the foregoing Parts pinpoint numerous ways in which approaches to maximizing the value and impact of IARC's work can be further strengthened.

- 87. Several as-yet-untapped possibilities were raised in addition to the areas described above. Some, for example, attached importance to the role of ex-graduates or of ex-interns and visiting scientists in returning to their countries and being "ambassadors" of IARC and disseminating its value and impact in their home countries. Others argued that because IARC does not do work on cancer treatment and disease management, the most concerned segment of global public opinion is not sensitized to the importance of IARC. By strengthening ties with the science community that is involved in therapy and bringing relevant findings of IARC research to them, some felt that an important element of public opinion would come around to seeing the value and impact of IARC. Some opposed such an approach as it deviates from IARC's mission and its research scope and capabilities.
- 88. Enhanced Participating State engagement constitutes one significant overarching area that some felt could help maximize IARC's value and impact. While currently 27 countries contribute financially to IARC through their assessed member contributions, the entire international community benefits from IARC's public goods a fact that some felt constitutes a message worth conveying in its own right. The desk review and interviews undertaken in this evaluation revealed that a significant investment of time and effort has been expended, not least of all by successive IARC directors at considerable opportunity cost to managing the agency, on growing the membership of the Governing Council. These efforts have yielded very few results, however. Accordingly, one other proposal arising during the evaluation is that IARC charge higher cost-recovery fees for the purchase of its publications and other products by cancer-related entities in non-contributing countries. This approach is not without controversy, however, as many argued that this fee-for-service model would be antithetical to IARC's provision of public goods to the entire international community including, and importantly, precisely those countries less able to afford to pay for such products.
- 89. The unifying thread underpinning all of these potential opportunities is the need to more successfully communicate its comparative advantage and accomplishments. As noted in Part A, while key stakeholders consulted in this evaluation can readily identify individual facets of this comparative advantage and value proposition, the IARC "brand" has not always been clearly, consistently and concisely communicated to key stakeholders in such a way as to achieve the ends described above (e.g., clearly delimited strategic priorities that are based on IARC's niche, enhanced visibility of IARC within WHO and with external audiences,

increased resources). Stakeholders consulted in this evaluation consistently cited communications as an area which has historically not been harnessed to its full potential.

- 90. Important steps have been taken to remedy this gap. As noted in Part B of this report, the role definition of the Liaison Officer cum Chief of Communications represents a significant step that can help remedy this gap. As a further step toward this end, in late 2018 IARC developed a communications strategy which takes stock of the successes and challenges of the previous five years and provides an analysis of the current communications activities. It aims to define the overall goal, the strategic objectives, these being to:
  - raise awareness of IARC's mandate and activities among all identified stakeholders;
  - ensure IARC is perceived as a leading research agency in cancer prevention globally; and
  - reinforce confidence and trust in IARC's activities as well as promote a positive image through consistent and clear messaging, including in relevant areas with the WHO.

The strategy also formulates communications priorities for the following five years and proposes a plan of action to successfully achieve these by reaching key target audiences.

- 91. Moving forward, translating the IARC brand into a well-tailored set of messages, delivered to distinct audiences by the most appropriate messengers through the most fit-for-purpose channels, will constitute a key area for action. As per the communications strategy, these key audiences include: the scientific community, governments, public health decision makers and other relevant entities in cancer research and public health, the media, and the general public.<sup>25</sup> With specific regard to communications in pursuit of resource mobilization objectives (see para 83), it will be imperative that IARC's resource mobilization efforts are supported closely by relevant communication and outreach activities.
- 92. One vital element of these communication and resource mobilization efforts is the strategic use of information and knowledge from IARC's work its research projects as well as its publications as the raw material for such communications. The desk review component of this evaluation determined that such information and knowledge are rarely collected or shared in a way that could be packaged and used to communicate with IARC's target audiences. There are examples where key IARC research projects were not clearly branded as IARC or opportunities to communicate have been lost. In some instances, this missed opportunity is owed to the preferences of partners, who can be reluctant for IARC to communicate on a project funded by them or who might impose specific communications agreements in their contracts. As a result, the launch of data, reports or studies is sometimes planned and decided

<sup>&</sup>lt;sup>25</sup> Specific target audiences highlighted in the strategy are: -Key stakeholders and decision-makers: such as Ministers of Health, among others - Partner organizations: other relevant research agencies, e.g. US NCI, ACS, CRUK, WCRF, INSERM, INCa, UICC, Cancer registries, Cancer Associations etc.- IARC: Participating States, Governing and Scientific Councils.-WHO DCO and other relevant WHO contacts - Scientific community: leading cancer research centers and institutes (non-governmental, governmental, non-profit, private sector); leading researchers, academics, and experts in cancer, health, research, environment, or science, and Civil society: relevant advocacy groups, patient groups, and organizations/association.

by partners rather than by IARC, with limited or no credit to IARC. These circumstances can deprive IARC of key branding and positive coverage regarding its activities to the advantage of other organizations.

- 93. A further challenge in the implementation of the communications strategy centers on the role of the Chief of Communications. Although this role, as noted above, was defined in August of 2017 this otherwise positive measure entails a potential risk as well: the current Communications Unit in the Director's office has been assigned the demanding dual role of implementing the communications strategy as described here and with the coordination of the interface and collaboration with pertinent WHO units. It remains to be seen whether this dual role is sustainable within the current resources allocated to the function.
- 94. A challenge to communications efforts, cited in a handful of interviews, is the lack of a clear focus on the longer-term results and outcomes IARC is aiming to achieve through its research projects in terms of public health and folding the findings into its communications messages. These stakeholders argued that a clear message of this longer-range focus could help communicate IARC's *raison d'être* in a compelling manner to key audiences. One means of helping IARC take this longer-range focus is through an enhanced MTS process including by rooting its work in higher-order goals such as the GPW13 and SDGs. (See Part A.)
- 95. Another is through enhanced collaboration with the WHO at the nexus of cancer research and public health and public policy; in forging stronger collaboration in this area, IARC could embed its research within the larger long-term goals of cancer reduction, as well as cancer-related morbidity and mortality. Toward this end, some stakeholders maintained that IARC should be involved in the WHOs policy matrix and in the WHOs work groups on cancer.

## **Key Findings**

- The previous Parts of this report identify numerous successes and outstanding gaps related to IARC's approaches to maximizing its value and impact e.g., through sharper strategic planning processes, enhanced collaboration with WHO and other partners, and strengthened resource mobilization efforts.
- **Potential measures to maximize value and impact were identified**, including efforts to expand membership of the Governing Council, harnessing the role of IARC-trained scientists, visiting scientists and cancer leaders as potential IARC "ambassadors," and expanding linkages to the international cancer treatment community.

#### Recommendations

• IARC should formalize closer integration and information exchange between its Governing and Scientific Councils.

# Conclusions and way forward

- 96. In this evaluation, the Advisory Group was able to incorporate input from the Governing Council and Scientific Council as well as IARC and the WHO personnel, coupled with information and data extracted from an extensive range of documents covering IARC's work. Within this context, and with additional inputs and discussion at an in-person meeting in October 2019, the Advisory Group concluded that IARC continues to fulfill an essential role in the global evaluation of cancer etiology, surveillance, prevention and control in addition to training, in line with its mandate as described in the Statute. It has additionally provided research bridges for low- and middle-income countries when few other institutions were present in this space. Despite a far smaller budget in comparison to other international cancer research institutions, IARC has maintained high levels of productivity, scientific rigor and effectiveness in generating research of significant benefit to the international community. In addition, future public communication about cancer risks and hazards is now being guided through standard operating procedures aimed to ensure consistency of messaging between IARC and WHO.
- 97. Notwithtanding this positive assessment, the Advisory Group also concluded that there are several important gaps impeding IARC from enhancing its strategic positioning within the international cancer research landscape and fulfilling its mandate in the most relevant, effective and efficient manner possible. In particular, strategic prioritization has not been as inclusive, transparent or focused an exercise as it could be: despite broad alignment of IARC's research activities to its mandate, the MTS development process has not historically been used as a means of making clear strategic prioritization decisions (what it will and will not pursue and why), as rooted in a clear articulation of its own comparative advantage (or value proposition) in relation to other cancer research institutions and a clear consideration of its research constraints. Moreover, the communications function has to date been focused narrowly on addressing the aforementioned risks (and reactively responding to the results) of uncoordinated public communications by IARC and WHO; moving forward, there is room for this function to play a significantly more positive, proactive role in the service of shaping public awareness of IARC and its work. In this respect and beyond, there is also room for strengthened interlinkages between IARC and WHO, particularly with WHO's Science Division now firmly in place, and between IARC's communications and nascent resource mobilization functions.

## Recommendations

98. Based on its analysis, the Advisory Group makes the following ten recommendations:

- 1. To maximize its impact in the face of its resource constraints, IARC should engage in an inclusive, transparent and focused strategic prioritization process during the development of the MTS 2021-2025 within its defined emphasis on surveillance, causes and prevention of cancer, and capacity building.
- 2. As WHO's newly established Science Division shapes its research agenda for the Organization, Director IARC, working with the Science Division through WHO's Chief Scientist and engaging the support of WHO's leadership, should:
  - a. ensure the inclusion of WHO, through its Chief Scientist, in the MTS 2021-2025 development process;
  - b. articulate and implement a joint strategy for improving communication between IARC and WHO, with a view to achieving gains in efficiency, transparency and effectiveness, as well as to further pre-empting and reconciling situations where IARC and WHO might otherwise have divergent public statements on a given topic;
  - c. identify and pursue relevant, concrete opportunities for bringing the added value of IARC's substantial scientific expertise in cancer prevention and control to bear on WHO's research agenda; and
  - d. seek to produce, together with WHO, a range of relevant co-owned and co-authored technical documents that involve a review of scientific knowledge and policy or clinical recommendations.
- 3. IARC, working with WHO, should ensure that efforts currently underway to synchronize the IARC Governing Council and the WHO Executive Board meetings are realized, thus enabling participation of IARC and WHO management and staff in each other's governing body meetings.
- 4. The move to the Nouveau Centre provides an opportunity for IARC to undertake a strategic planning process to optimize planning for the future and consider which are the core inhouse laboratory capacities to be incorporated in the new building and which are best obtained through collaborations with external laboratories to maximize efficiencies. Toward this end, IARC should:
  - a. develop a more detailed description of the process it has been using to ensure efficiencies in decisions on core in-house laboratory capacities versus collaborative laboratory capacities and share this information with the Scientific Council and Governing Council, thus providing examples of how this process has been implemented with some specific projects; and

- b. use the MTS 2021-2025 consultation process to explicitly include an in-depth discussion of this key aspect of IARC's work, based on a review of relevant evidence and data, resulting in a clear strategy for balancing its internal and external laboratory facilities to be implemented moving forward.
- 5. As bioinformatics needs are an increasingly important component of laboratory capacity, IARC should regularly update the Scientific Council and Governing Council on the computational and data storage needs for bioinformatics into the future.
- 6. Given its financial constraints, IARC should intensify its efforts to obtain additional laboratory, bioinformatics, and other disciplinary expertise through collaboration, Visiting Scientists, and secondments from Participating States and other partners. The result of these efforts should be incorporated into the aforementioned for balancing its internal and external laboratory facilities or in a separate strategy to be implemented moving forward.
- 7. IARC's biobank is essential to fulfil its global role in international study coordination and science contributions. In order to enhance its capacity, IARC should:
  - a. undertake regular assessment of the value of keeping older, legacy samples;
  - b. ensure that the proportion of IARC biobank samples/usage that are represented by the EPIC study are assessed with respect to value for money to IARC;
  - c. conduct an assessment of whether charge-back costs are compatible with similar biobanks internationally;
  - d. enhance online transparency of IARC biobank sample sets and access regulations, as a matter of priority;
  - e. streamline the process for engaging in public/private collaborations using the biobank;
  - f. consider efficiency trade-offs for the location of the biobank on site or at a remote location; and
  - g. analyze policy constraints and sample ownership changes that could facilitate largescale analysis of specimens by commercial companies.
- 8. IARC should assess whether its collection of biological samples is optimal in view of IARC's global mission. Toward this end:
  - a. The balance between developing new biobank resources and sustaining the existing biobank should continue to be carefully considered; and
  - b. IARC should exercise its convening power to increase access to the biobank and data across consortia in an equitable manner.
- 9. In order to ensure the future financial sustainability of its research, IARC should, beginning with its MTS 2021-2025 process and the ensuing budgeting, communications and resource mobilization work:
  - a. identify core priorities and core staff and fund these through the 70% regular contributions, with additional activities and costs also being prioritized and paid from the 30% voluntary contributions;

- b. identify efficiency gains, e.g. negotiate more flexible contracts for staff on external grants;
- c. continue to develop a fit-for-purpose, cost-efficient Nouveau Centre;
- d. intensify efforts to ensure that programme support costs related to external grants are maximally covered, i.e. not subsidized by regular contributions;
- e. strengthen efforts to find (recruit) new Participating states, including by showing them the clear added-value for membership of IARC as well as their existing membership of WHO;
- f. continue efforts to improve and professionalize its fundraising strategies, including more effective communication of IARC's successful research and capacity-building work as a means of showcasing its value to prospective donors;
- g. explore the possibility for naming rights and endowments by philanthropists;
- h. articulate the economic case for the public health impact of IARC's work including for capacity building in LMICs so that IARC may qualify for funding from major development aid agencies and international finance institutions;
- i. establish a mechanism to advise the Director on IARC's future business model and its financial sustainability, either by convening a group of experts, or by appointing a professional external consulting partner;
- j. IARC's comparative advantage and value proposition should be thoughtfully discussed and clearly articulated in the MTS 2021-2025 development process, then used as the basis for developing a communications strategy (and associated communications plan) aimed at showcasing the Agency's unique contributions to cancer prevention and control as a means of harnessing its full potential.
- 10. IARC should formalize closer integration and information exchange between its Governing and Scientific Councils.
- 99. The Advisory Group acknowledges that IARC has already undertaken important steps to address aspects of several of these recommendations. It also recognizes that the MTS 2021-2025 development process serves as a key platform for shaping IARC's future in the medium term. The Advisory Group thus encourages IARC to seize on this process as an opportunity to strengthen or accelerate momentum on those actions already underway and for actioning the Advisory Group's additional recommendations.

# Annexes

	Title	Document (hyperlink)
Annex 1	Desk Review Summary	Annex 1
Annex 2	Interview Summary (IARC and WHO Staff)	Annex 2
Annex 3	Summary Survey Data (Governing Council)	Annex 3
Annex 4	Summary Survey Data (Scientific Council)	Annex 4
Annex 5	Summary Survey Data, Questionnaire (IARC staff)	Annex 5