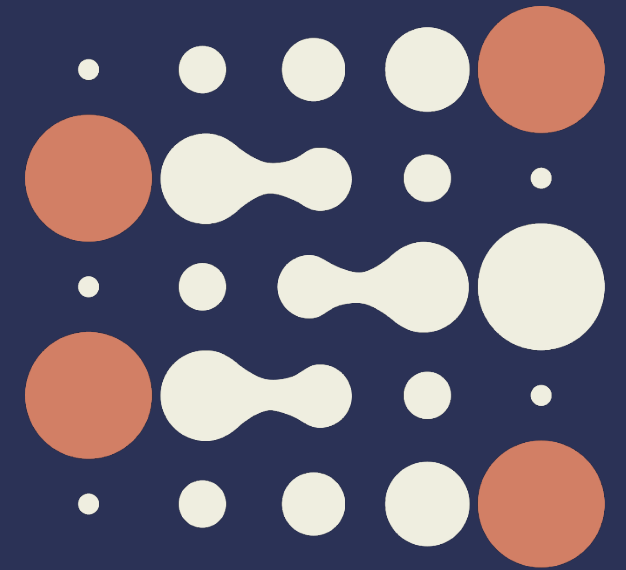


Director's response to the Cancer Surveillance (CSU) Branch Review

International Agency
for Research on Cancer



*Scientific Council 59, item 6,
8 February 2023*



Reviewer's Panel's comment

The RP recommends strong support for CSU future plans to maintain IARC's position as a premier provider of global cancer surveillance and descriptive epidemiology research. The RP recognizes CSU leadership has been outstanding as demonstrated by their excellent experience and track records.

Response:

Positive recommendation, gratefully received. No further comment.

Reviewer's Panel's comment

CSU (Data for Action) is one of the four IARC pillars and is currently underfunded. Despite increasing needs of cancer data provided by CSU, limited RB funding and reliance on EB funding for core activities is a persistent and critical concern, which may cause systematic exhaustion of the Branch and lack of fulfilment of the IARC MTS. The RP recommends ensuring adequate administrative assistance for securing EB funds. The RP advises the IARC Director to substantially increase secure support to CSU over the long term from RB funding, even if this requires commensurate reductions in other activities.

GICR is an essential part of CSU and it provides the scaffolding and standards for cancer registries all over the world. The RP recommends that this important part of the CSU Branch be covered entirely and securely with RB funds, including the GICR leadership.

Response:

- The IARC Director is making every effort to ensure secure support for CSU and GICR.

Reviewer's Panel's comment

All CSU activities directly link to the IARC mission as the most standardized and reliable global cancer data provider, playing a vital role in both national, regional and global health policy. Increased timeliness of the data is important. The RP encourages CSU to proceed with obtaining cancer registry data more frequently (biannually/annually).

Response:

- Building on the development of *Cancer Over Time*, a tool for the geographic and temporal analysis of individual registry datasets accepted in the twelve CI5 Volumes is being built.
- To ensure the IACR website contains timely registry data independent of the CI5 cycle, registries included in CI5 will be asked on a voluntarily basis to submit (aggregated) datasets for more recent complete years, annually, starting in late-2023.

Reviewer's Panel's comment

The RP recommends that CSU continues to develop their new solutions that can handle data flow impediments caused by stricter data sharing legislation worldwide. The proposed emphasis on aggregate data, and novel methods such as federated analysis and synthetic data seems wise. RP also recommends that CSU work with IARC leadership to encourage WHO and UN to find longer-term solutions for data sharing agreements with countries worldwide.

Response:

- IARC as part of the WHO and the UN system, is not subject to any particular data protection law or regulation. Due to the privileges and immunities of IARC, it is equally not subject to oversight of a data protection authority. A basic framework for the processing of personal data by, or on behalf of, the UN System Organizations in carrying out their mandated activities has been set out, and discussions with the European Commission and other bodies are ongoing.

Reviewer's Panel's comment

The RP recommends CSU develop a transparent system to strategize and prioritize future projects, incoming ideas and new collaborations with greater collective strategic clarity to assist with managing workloads. Strategic positioning relative to other large international descriptive (cancer) epidemiology efforts would be valuable for CSU.

Response:

- CSU will undertake several strategic retreats in 2023 to re-examine our future projects in the context of our medium-term goals and map these to the activities of likeminded institutions.
- The aim will be to streamline CSU activities, set out priority areas, and further extend key collaborators as a means to drive our strategic ambitions and increase internal efficiency - while avoiding unnecessary duplication of efforts.

Reviewer's Panel's comment

The further development of the e-tools pipeline from cancer registration to cancer statistics (CanReg5, CanStaging+) combined with harmonization of cancer data is encouraged by RP.

Response:

- Connecting CanReg5 with DHIS2 and other facility-based data platforms is a priority for CSU, given the potential in increasing both registry efficiency and quality.
- The potential uptake and benefit of connecting DHIS2 to CanReg5 for the purposes of sharing between the systems is receiving great interest from Ministries of Health given its direct application to cancer data capture.

Reviewer's Panel's comment

The proposed new global indicators, such as productivity losses and DALYs, describe the cancer burden beyond the traditional measures and are endorsed by RP. RP recommends CSU further pursue country level PAFs of cancer risk factors started at IARC to the predictions of cancer burden. This will support future preventive cancer policies and preventive efforts globally.

Response:

- CSU is investigating options that maximise efficiency and collaboration in the development of PAF and other key indicators for cancer prevention.
- The multi-partner approach to estimating the proportion of cancers attributable to lifestyle and environmental risk factors in France was highly productive (20 published papers) and provides a template for country engagement, as well as regional and global indicator development.

Reviewer's Panel's comment

New programmatic areas covered by CSU, including health economics and social inequalities are prioritized in MTS. For these important programme areas to thrive, the RP recognizes that these areas will need continued attention and support.

Response:

- Agreed. While CSU has sought to identify programmes of work prioritised in the Medium-Term Strategy (MTS), including the “economic and societal impact of cancer” – the complete delivery of the milestones and deliverables relies on a build-up of resources over the next years.
- Hence a controlled expansion of the two teams, the Cancer Inequalities Team (CIN) and Health Economics and Cancer (HEC) is envisaged but the corresponding work plans are scalable, dependent on both the extent of internal and external collaboration as well as the increasing availability of additional staff/funds.

Reviewer's Panel's comment

CSU must maintain a strong commitment to leading and conducting innovative data science in surveillance research consistent with its international leadership position. Specific suggestions for areas of continued scientific focus might include: methods for integration and harmonization of complex diverse data sources; artificial intelligence and machine learning; methods for causal inference; federated data analysis methods or synthetic data methods.

Response:

- CSU will examine these scientific areas in detail in the planned strategic retreats.
- A major focus already is the use of federated methods for survival analysis though there are concerns whether these are viable solutions in LMIC, where, for example, registries often have limited in-house IT and statistical capacity.
- With the CI5 evaluation becoming larger and more complex, a search for AI tools geared towards the systematic evaluation of incidence data to aid quality assessments is underway.

Reviewer's Panel's comment

The RP recommends CSU reflect on opportunities to create/curate data resources that could be a true global public good and increasingly amenable to access and/or analysis by researchers globally outside IARC. Even among ongoing international cancer surveillance efforts, IARC CSU is in a highly unique position to generate such global public goods in a manner consistent with the IARC mission while recognizing data privacy regulations worldwide.

Response:

- CSU is investigating the development of tools for the local analysis of our global data resources with national partners. The SEER*Stat statistical software provides one mechanism for the analysis of cancer-related databases that could serve as a starter template.

Reviewer's Panel's comment

The RP recommends monitoring the impact and influence of CSU outputs in terms of health policy using research impact tools (e.g. overton.io.). This will assist in maintaining visibility of CSU's expanding brands and target CSU's dissemination. Documenting policy uptake of CSU outputs may also assist in promoting CSU's impact and contribute to IARC philanthropic donations and fund-raising efforts.

Response:

- CSU has been closely monitoring the (research and web) impact of our output, but has not undertaken a direct assessment of policy uptake, which, as stated, is critical to ensuring our future relevance and bringing in the necessary resources to continue to expand and innovate.
- CSU is thus currently investigating policy impact tools such as Overton, and how we might use them in our daily work, and for the purposes of advocacy.

Reviewer's Panel's comment

The RP recommends aggressively pursuing suitable opportunities for grant funding based on their strong body of work and continued commitment to innovative data science. The emerging areas of social inequalities and descriptive economics will add to existing CSU competitiveness and collaborations for grant funding from diverse international funders.

Response:

- CSU is pursuing funding models with many partners to ensure efficiencies and innovation within our surveillance and research programmes.
- As stated, the controlled expansion of the programmes of work under the banner of “economic and societal impact of cancer” is itself dependent on an increasing availability of additional resources.