






# Impact of the COVID-19 pandemic on population-based cancer registry

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## Abstract

The COVID-19 pandemic has caused disruptions to national health systems and impacted health outcomes worldwide. However, the extent to which surveillance systems, such as population-based cancer registration, have been affected was not reported. Here we sought to evaluate the effect of the pandemic on registry operations across different areas and development levels worldwide. We investigated the impact of COVID-19 on three main areas of cancer registry operations: staffing, financing and data collection. An online survey was administered to 750 member registries of the International Association for Cancer Registries. Among 212 responding registries from 90 countries, 65.6% reported a disruption in operations, ranging between 45% in south-eastern Asia and 87% in the Latin America and Caribbean. Active data collection was disrupted more than case notifications or hybrid methods. In countries categorized with low Human Development Index (HDI), a greater number of registries reported a negative impact (81.3%) than in very high HDI countries (57.8%). This contrast was highest in term of impact on financing: 9/16 (56%) registries in low HDI countries reported a current or an expected decline in funding, compared to 7/108 (7%) in very high HDI countries. With many cancer registries worldwide reporting disruption to their operations during the early COVID-19 pandemic, urgent actions are needed to ensure their continuity. Governmental commitment to support future registry operations as an asset to disease control, alongside a move toward electronic reporting systems will help to ensure the sustainability of cancer surveillance worldwide.

## KEYWORDS

COVID-19 pandemic, impact, international, population-based cancer registry

## What's new?

The COVID-19 pandemic has caused disruptions to health systems worldwide. Has it also affected surveillance systems, such as population-based cancer registries? In this study, the authors found that two-thirds of analyzed cancer registries reported disruption in staffing, finances, and/or data collection. In countries with a low Human Development Index (HDI), a

greater number of registries reported a negative impact (81.3%) than in very high HDI countries (57.8%). These results emphasize the need for actionable, strategic plans to ensure the continuity of registry operations globally.

## 1 | INTRODUCTION

Several studies have reported substantially higher morbidity and mortality from COVID-19 among patients with cancer.<sup>1,2</sup> Additionally, the COVID-19 pandemic has had far-reaching consequences on the delivery of activities across the cancer continuum, including national screening programs and cancer care.<sup>3</sup> As an indirect consequence of national responses to the early phase of the COVID-19 pandemic, there were delays in diagnoses, referrals and testing of symptomatic cases; delays or changes in cancer management; and changes in the provision of palliative care.<sup>4,5</sup> In the Netherlands, a decrease in recorded cancer cases during the 2.5 month lockdown was attributed to patient's concerns about possible exposure to SARS-CoV-2 in a health-care setting, and decreased interaction with clinicians linked to social distancing and lockdown policies.<sup>6</sup> In Italy, pathology departments, an important data source for cancer registries, have reported 39% fewer cancer diagnoses in this period compared to average numbers in previous years.<sup>7</sup> The temporary suspension of cancer screening programs has also been reported as a further cause of reduced cancer diagnoses during the lockdown.<sup>4,8</sup>

Population-based cancer registries (PBCR) produce incidence and survival at the population level to monitor and evaluate of cancer control interventions, and thus the provision of an evidence base for the development of national cancer control plans. During the COVID-19 pandemic, registries provided valuable insights into health system disruptions to cancer diagnosis and cancer care pathways, and the estimation of the direct or indirect impact of the pandemic on cancer outcomes.<sup>4,5,9</sup> As with many institutions during the pandemic, the operations of PBCR have been affected. In our study we sought to assess the impact of the first wave of the pandemic on cancer surveillance systems globally.

## 2 | METHODS

A questionnaire comprising 33 questions (64% closed-ended—ordinal or nominal, with some dependent on preceding answers) was formulated to assess disruptions to cancer registry operations early in the COVID-19 pandemic (provided in Appendix S1). The questionnaire was structured into three major areas of potential disruption: (a) staffing, (b) financing and (c) data collection.<sup>10</sup> Two aspects of data collection were investigated, namely “passive” collection, where data retrieval relies on health workers to complete notification (e-)forms that are then forwarded to the registries, as well as “active” collection where registry staff visit the various data sources to identify and

abstract the relevant data. Additionally, an open-ended question to assess contingency strategies that have been implemented at the registry to minimize the pandemic's impact on registry operation was also asked. The questionnaire was developed in an iterative process and tested by research team members and additional reviewers from registries for face validity and readability. The original survey in English was translated in French, Spanish, Portuguese and Japanese. It was estimated that the survey took 15-20 minutes to complete.

The survey was then sent to 750 cancer registries in 160 countries according to the membership of the International Association for Cancer Registries. It was administered online using Research Electronic Data Capture (REDCap) and analyzed in Stata 14. The survey was emailed on 8 May 2020 and closed on 8 June 2020, with one reminder sent to registries that had not yet responded during this period.

We examined national responses toward the outbreak in different world regions (South-East Asia, Caribbean and Latin America, Europe, North America, Middle East and North Africa, sub-Saharan Africa and Oceania) and categorized countries into the four-tier human development index (HDI)<sup>11</sup> to assess impact according to national development levels. Frequencies and proportions were calculated for questions with ordinal or nominal categories. Open-ended questions were assessed for common themes and important factors to help explain local issues.

## 3 | RESULTS

Of the 230 registries that responded, 18 had a high degree of missing data and were excluded. The remaining 212 valid responses from 90 countries were included in the analyses. There were 203 general PBCRs (collecting cancer data for all age groups and cancer sites) and 9 pediatric or specialized PBCRs (collecting data on a defined section of population). In total, 65.6% (n = 139) of respondents reported a change (responded “Yes” to “Have your registry operations (including staffing and funding) been affected by COVID-19?”) in the cancer registry operations (Table 1); this proportion ranged between 45% in South-East Asia to 87% in the Caribbean and Latin America (Figure 1). When categorized by HDI, the changes in registry operations ranged between 57.8% (n = 63/109) in countries with very high HDI to 81.3% (n = 13/16) in countries with low HDI. Of the three registry operation themes potentially impacted, namely staffing, financing and data collection, the latter was the activity most frequently affected, with 54% (n = 115) of registries reporting some disruption. Additionally, 26% (n = 56) of registries were subject to changes in staffing and 18% (n = 37) suffered from financial cuts (Table 1).

**TABLE 1** Reported global impact of COVID-19 pandemic on three areas of population-based cancer registries' operations (N = 212), as reported in May to June 2020

Affected staffing			Affected financing			Affected data collection		
Among all responding registries	56 (212)	26.4%	Among all responding registries	37 (212)	17.5%	Among all responding registries	115 (212)	54.2%
Among registries with affected operations	56 (139)	40.3%	Among registries with affected operations	37 (139)	26.6%	Among registries with affected operations	115 (139)	82.7%
Causes			Usual sources of funding			Usual data sources		
Inadequate working conditions	32 (56)	57.1%	National government	26 (37)	70.3%	Public/university hospital medical records	98 (115)	85.2%
Reassignment	29 (56)	51.8%	Hospital-based funds	12 (37)	32.4%	Specialist oncology units	94 (115)	81.7%
Care for family members	27 (56)	48.2%	Academic institution	11 (37)	29.7%	Private hospital/clinic medical records	90 (115)	78.3%
Sick-leave	18 (56)	32.1%	Local nonprofit	10 (37)	27.0%	Pathology laboratories	90 (115)	78.3%
Cutback working due to reduced funding	14 (56)	25.0%	Research grant	9 (37)	24.3%	Radiotherapy records	77 (115)	67.0%
Other	10 (56)	17.9%	Other	9 (37)	24.3%	Outpatient records	70 (115)	60.9%
Resignation/dismissal	9 (56)	16.1%	Private companies	6 (37)	16.2%	Hematology laboratories	70 (115)	60.9%
			International nonprofit	6 (37)	16.2%	Vital statistics	56 (115)	48.7%
			Charities	6 (37)	16.2%	Imaging center records	53 (115)	46.1%
			Individual donor	6 (37)	16.2%	Screening programs	44 (115)	38.3%
			Health insurance companies	4 (37)	10.8%	Other laboratories	44 (115)	38.3%
						Hospices records	32 (115)	27.8%
						Autopsy reports	31 (115)	27.0%
						Health insurance	22 (115)	19.1%
						Others	9 (115)	7.8%

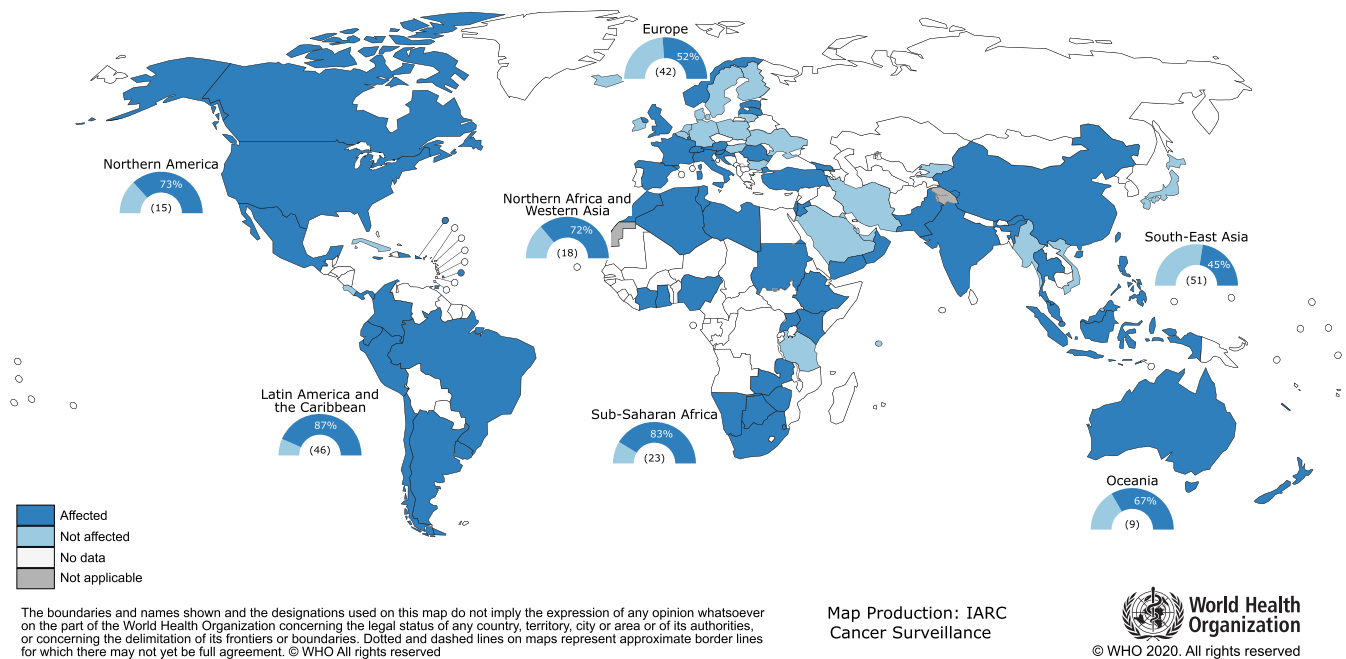
The impact on staff was mainly related to inadequate working conditions (57%, n = 32), reassignments to other departments (52%, n = 29) or staff having to care for family members (48%, n = 27). There was no clear pattern of staff disruption by HDI category (Table S1), yet more frequent disruption in registry staffing was seen in the Middle East and North Africa (56%, n = 10/18), and Caribbean and Latin America (44%, n = 20/46) compared to South-East Asia or sub-Saharan Africa (9%, respectively n = 2/22 and n = 5/54) or Oceania (10%, n = 1/10) (Table S2).

The reported or expected reduction in financing was greatest among registries that were dependent on governmental funding (70% of financially affected registries, n = 26). Reductions in financing were also reported in other settings, including registries based in hospitals (32%, n = 12), and those based in, or funded through, academic institutions (30%, n = 11), local nonprofit organizations (27%, n = 10) or research grants (24%, n = 9). A clear pattern was seen by HDI level (Table S3); the proportion of registries reporting financial reduction was largest in low and medium HDI countries (56%, n = 9/16 and 32%, n = 6/19, respectively) and smallest in high HDI countries (23%,

n = 15/66 in high HDI, and 7%, n = 7/108 in very high). According to world region (Table S4), 48% (n = 11/23) of PBCRs in sub-Saharan Africa reported a reduction in financing, followed by 28% (n = 12/43) and 22% (n = 4/18) of PBCRs in the Latin America and the Caribbean, and North Africa and the Middle East, respectively.

Finally, a complete disruption of passive data collection varied from 2% to 17% of impacted registries across data sources (Table S5), while complete disruption to active data collection was even more common, ranging between 4% and 44% across sources. A marked contrast in the impact on data collection was seen by HDI group (Table S6), with collection impacted in 75%, 63%, 60% and 46% of registries in low HDI through to very high HDI countries respectively; those particularly affected were located in Latin America and the Caribbean and (85%, n = 39/45) and sub-Saharan Africa (74%, n = 17/23) (Table S7). Registries with disrupted data collection reported a reduction in registrations ranging from 8% to 85% across sources (Table 1), with the highest disruption in active access to medical records (public: 85%, n = 98 and private clinic: 78%, n = 90), specialist oncology units (82%, n = 94) and pathological laboratories (78%, n = 90).

## Registry operations



**FIGURE 1** Global map showing countries where population-based cancer registry operations (staffing, financing and data collection) were affected by the COVID-19 pandemic (dark blue) and summary results by world region (% affected and number of cities covered by at least one responding PBCR per region) [Color figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

## 4 | DISCUSSION

In our study we have shown that the COVID-19 pandemic has disrupted surveillance operations in two-thirds of all responding population-based cancer registries worldwide. Overall, the registries reported disruption in data collection (54%,  $n = 115$ ), followed by staffing (26%,  $n = 56$ ) and registry financing (18%,  $n = 37$ ). While data on the impact of the pandemic on cancer diagnoses and outcomes continue to accumulate, to the best of our knowledge this is the first report on the impact on registry operations.

We found that the impact on the PBCR's operations mainly stems from the inability to actively retrieve data from the usual sources of information (as reported by 54% of participating registries). Disruption in data collection was noted with respect to the retrieval of medical records in hospitals, and access to data in specialized oncological units and pathological laboratories<sup>6</sup>; traveling restrictions imposed by lockdowns may partly be responsible for this. As the world experienced the COVID-19 pandemic to varying degrees and at different time points, the patterns of governmental response varied by country and over time,<sup>12</sup> resulting in uneven impact on cancer services and cancer registry operations. In high and very high HDI countries in Europe, North America and parts of south-eastern Asia where COVID-19 has had the hardest impact at the time of the survey, and were followed by some of the strongest national responses to the epidemic, we found a smaller impact on PBCR operations. This may be linked to the more mature PBCR system supported by adequate resources and technological innovations.<sup>13</sup> As such, issues surrounding data access

may be counteracted by a better remote access to the data sources along with the expansion of the use of electronic medical records, where applicable and feasible.

The development of innovative IT solutions and the ability to import data from sources electronically is key to future sustainability of PBCRs. About 45% of included PBCRs reported that contingency measures have been taken to mitigate impact of the pandemic, including enhanced IT capacity and security. Rapid technological uptake and implementation during this early period of the pandemic have been raised by many registries as a silver lining of the pandemic. Disruption to data access was clearly related to HDI status, with registries in low and medium HDI countries most affected, highlighting the urgent need to address the technology gap to remedy health inequalities in the very regions where cancer data is lacking.<sup>14,15</sup> In reality, many registries struggle with their current financial situation, that particularly in registries in sub-Saharan Africa (48%). Studies have shown that resource requirements for cancer registration is relatively modest, ranging from US \$3.77 to US \$15.67 per cancer case in low to middle income countries.<sup>16</sup> The need for increased financial support as well as technical assistance to bring innovation to cancer registration in these settings is even greater in the present context of the pandemic.

In addition to operational factors, various external factors have caused additional challenges for cancer registries to deliver on their mandate in providing a comprehensive and timely situation analysis of the cancer burden. In the national registry of the Netherlands, a 27% drop in the number cancer cases was reported due to a decrease in data flow from pathology departments and referrals for cancer

diagnosis by general practitioners<sup>6</sup> as well as the suspension of several cancer screening programmes.<sup>4</sup> Similar declines have also been reported in Belgium and Slovenia.<sup>5,17</sup> Suspended population-based screening programs during the lockdown resulted in lower case detection and diagnosis of breast and colorectal cancers.<sup>4</sup> However, number of new cases has also dropped for nonscreened cancers suggesting a decrease in the number of cancer diagnoses in general.<sup>18</sup> Further to the disruption and delays in diagnostic pathways, delays in cancer care such as surgery<sup>19</sup> may further impact cancer numbers. In addition, patient factors—including anxiety to consult their attending physicians, or anxiety of contracting COVID-19 in health care setting—may have resulted in fewer medical check-ups.<sup>20</sup> In our study, 53% (n = 112, data not shown) of the participating registries expected that the reduced collection of data could potentially be rectified when lockdown is lifted. Methodology to correct reporting delays have previously been used,<sup>21</sup> and today knowledge transfer of these methods may assist in national monitoring and planning of cancer control strategies.

In conclusion, almost two-thirds of all participating PBCRs reported disruption in their operations ranging from staffing, financing and data collection. The results confirm the expected that the proportion of registries reporting the largest disruption was in low and medium HDI countries, linked to the very fragile financial and organizational structure of many PBCRs in this setting. We highlight here the need for urgent action to minimize the long-term impact of the COVID-19 pandemic, especially in low HDI countries, many of which situated in sub-Saharan Africa. We noted a relatively low response rate from registries in Russian-speaking countries, and in the future, survey translated to Russian language may increase the responses from the region. We also could not assess the status of operation of registries that did not respond to this survey. Some PBCRs might have been closed or suspended during the peak of the pandemic, and therefore not represented in our study. Furthermore, in country where multiple registries exist, within country variation is not reported here and may need further examination. The consequences to health system monitoring can be mitigated through several focus areas. These include the provision of long-term governmental support, improvements in registry's infrastructure, including an expansion of electronic medical record reporting, and an increase in passive data collection. Delivering on these actions may limit the impact of the pandemic on current and future cancer patients and support the sustainability of cancer registries as the global eyes and ears of cancer control.

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## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of our study are available upon reasonable request from the corresponding author.

## ETHICS STATEMENT

Ethical approval for our study was not sought for as the unit of analysis was cancer registry. No personal information was requested in the survey. This work also makes part of the routine work of global cancer registry operation monitoring that has been mandated by the WHO to IARC. The survey request was accompanied with an information describing the study objectives and methodology. Data was fully anonymized for analysis in a central secure server at the International Agency for Research on Cancer.

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### SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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