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Uganda experience—Using cost assessment of an established registry to project resources required to expand cancer registration

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ABSTRACT

Background: The objectives of this study are (1) to estimate the cost of operating the Kampala Cancer Registry (KCR) and (2) to use cost data from the KCR to project the resource needs and cost of expanding and sustaining cancer registration in Uganda, focusing on the recently established Gulu Cancer Registry (GCR) in rural Northern Uganda.
Methods: We used Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*) to estimate the KCR's activity-based cost for 2014. We grouped the registry activities into fixed cost, variable core cost, and variable other cost activities. After a comparison KCR and GCR characteristics, we used the cost of the KCR to project the likely ongoing costs for the new GCR.
Results: The KCR incurred 42% of its expenditures in fixed cost activities, 40% for variable core cost activities, and the remaining 18% for variable other cost activities. The total cost per case registered was 28,201 Ugandan shillings (approximately US $10 in 2014) to collect and report cases using a combination of passive and active cancer data collection approaches. The GCR performs only active data collection, and covers a much larger area, but serves a smaller population compared to the KCR.
Conclusion: After identifying many differences between KCR and GCR that could potentially affect the cost of registration, our best estimate is that the GCR, though newer and in a rural area, should require fewer resources than the KCR to sustain operations as a stand-alone entity. The optimal structure of the GCR needs to be determined in the future.

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1. Introduction

Currently, most of the global cancer burden is occurring in low- and middle-income countries, and cancer diagnoses are predicted to substantially increase in Sub-Saharan Africa [1], indicating the need for country-specific evidence-based cancer control programs. Population-based cancer registries collect data necessary for planning and implementing cancer control and prevention programs, particularly in monitoring the effects of prevention, early detection, treatment, and palliative care [2]. A few countries in Sub-Saharan Africa, including Uganda and Zimbabwe, have longstanding population-based registries. The data from Sub-Saharan population-based registries reveal differences in cancer site and incidence rate trends by country, highlighting the need for more geographic coverage of cancer registration across Sub-Saharan Africa. This expanded coverage is needed to adequately document cancers of specific importance to each country so targeted interventions can be implemented [3,4]. Additionally, regional variation in cancer can exist within a given country. Therefore, adequate geographic coverage to capture these differences is required to develop optimal and cost-effective cancer prevention and control policies.

Abbreviations: KCR, Kampala Cancer Registry; GCR, Gulu Cancer Registry; CDC, Centers for Disease Control and Prevention; IntRegCosting Tool, International Registry Costing Tool; US $, United States Dollars; CI5, Cancer Incidence in Five Continents; INCTR, International Network for Cancer Treatment and Research; IARC, International Agency for Research on Cancer; UGX, Ugandan Shillings.

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The Kampala Cancer Registry (KCR), based in the Department of Pathology of the Makerere University College of Health Sciences, was established in 1954 and until recently was the only population-based registry in Uganda. The registry covers the population of Kyadondo County, which includes the city of Kampala and its surroundings [5]. The catchment area for the KCR has remained unchanged since 1954. Inhabitants come from all of the 31 ethnic groups found in Uganda, mostly from the Ganda ethnicity, but also includes many migrants from neighboring countries. The registry covers about 7.6% of Uganda's population and 0.8% of its total area. The KCR plays a major role in monitoring and evaluating cancer control measures in the region and country, in addition to its original role of cancer surveillance [5–7].

KCR produces high-quality data and has been a leader in supporting and expanding cancer registration in Uganda and Africa. There is a need to better understand trends and patterns of cancer in other areas across the diverse country, which includes 112 districts divided into 181 counties [8]. Uganda has many ethnicities and large differences between urban and rural areas, which can lead to regional differences in cancer incidence. The Gulu Cancer Registry (GCR) was established in 2014 to obtain information on cancer patterns in an area of northern Uganda that is very different – climatically, ethnically, and socio-economically – from Kampala. Fig. 1 shows a map of Uganda with the location of the KCR and GCR. The GCR is located in Saint Mary's Hospital, Lacor, a major referral center with the necessary diagnostic and treatment facilities to permit identification of cancer cases in the local area, and with a strong research interest in Burkitt lymphoma [9,10]. The GCR was initiated to collect all cases of cancers occurring in the population of the Gulu, Amuru, and Nwoya Districts. At the time of our study, the GCR was in its start-up phase of assessing cancer registration approaches, training registry staff, and assessing the quality of the initial data collection. The registry is supported by funds from a research project on Burkitt lymphoma. The GCR covers 2.2% of Uganda's total population, and about 5% of the total area.

Through this paper, we aim to determine the resource needs and cost of operating and sustaining cancer registration in Uganda. In 2015, we conducted an in-depth assessment of the cost of operating the KCR. We evaluated the similarities and differences between the KCR and GCR and used activity-based costs to project the possible costs and resources required to operate and maintain the recently established GCR since all components of registration activities have not yet been established in Gulu.

2. Material and methods

2.1. Kampala Cancer Registry data collection approach

The KCR uses a combination of passive and active approaches to data collection. In the passive method, certain health care providers (pathology laboratories) report data on cancer patients in their care to the registry. In the active method, cancer registrars visit health care facilities, such as Mulago Hospital, a 900-bed National Referral hospital with several units, to identify cancer cases. Active data collection is needed because Uganda does not have laws requiring health care facilities to report cancer cases to registries, but the KCR has some agreements in place for providers to allow data abstraction. The registry employs two registrars who travel to five other hospitals in Kyadondo County to obtain data at least once every 2 months. During these visits, the registrars consult the admission and discharge registers, clinical notes, and pathology reports. In addition to the two cancer registrars, record assistants in various units within the hospitals assist in extracting

Fig. 1. Uganda Map with Registry Locations.

data from the patient records. The registrars also routinely visit the Uganda Hospice to identify cancer patients. Certification of death is only carried out for legal reasons and is very incomplete, so the registry only uses death certificates issued in the Mulago Hospital mortuary as a source of information. The registry performs data management using the CanReg software [11], which includes checks for consistency and validity. The software also allows for searches to identify potential duplicate registrations. Only authorized personnel can access the registry data, and confidentiality is maintained by using only registration identifiers during data analysis.

2.2. Activity-based cost data collection

We used the *IntRegCosting Tool* to estimate the resource use by budget categories and to estimate the activity-based cost [12]. The *IntRegCosting Tool* consists of 10 modules that describe types of information, such as budget categories or other factors, and 30 activities that describe specific registry functions. The *IntRegCosting Tool* modules and activities have been described in detail previously [12]. The registry activities and definitions were tailored in consultation with registry staff, and matched to the categories used by other registries in low- and middle- income countries who pilot tested the *IntRegCosting Tool*. The registry provided information on labor and non-labor resources for each budget component and then assigned costs to 30 specific registry activities. Cost data were collected for 2014. The registry was able to accurately assign more than 95% of the contributions received to specific registration activities; the KCR was able to provide high-quality activity-based cost data using the criteria previously established for high-quality cost data allocation greater than 90% [13,14].

3. Calculations

3.1. Cancer incidence in the KCR and comparison with GCR

We determined the number of incidence cancer cases at the KCR from 1991 through 2012 and computed age-standardized incidence rates for the most recent 5-year period (2008–2012) using the direct method with the world standard population [15].

The number of cancer cases recorded by the KCR has continually increased over time, mainly because of growth and ageing of the county population as an increasing number of individuals come from rural to urban areas to seek work and better standards of living, but also because of increasing incidence rates for some of the major cancers [4].

The GCR is in the initial stages of population-based data collection, and therefore, only preliminary results, based on the 656 cases registered in 2013–2014, are available. Age-standardised rates were calculated as well for Kampala.

3.2. Cost estimation

We analyzed resource use and cost data using Microsoft Excel. We categorized the cost of the registry for each budget category, including labor, travel, equipment, and administrative or indirect costs. We summarized labor and non-labor information from the Microsoft Excel–based *IntRegCosting Tool* to determine the cost of specific registry activities.

We categorized the 30 registry activities into fixed and variable cost activities. By definition, fixed costs do not vary as the volume of cases changes (at least in the short run), while variable costs do change. The variable cost–related activities were further subdivided into core activities – those that were essential for registry operations – and other activities, such as advanced analysis (e.g., investigating disease clusters) and research-related tasks. We also report the cost per cancer case by activity type, which we calculated by dividing the total value of registry resources towards fixed cost, variable cost core, and variable cost other activities each by the average number of incident cases registered during a typical annual period (we used the 1907 incident cancers diagnosed in 2012).

3.3. Cost extrapolation

As stated in the introduction, the GCR was in its start-up phase at the time of the study. To project the possible cost of operating the GCR, we qualitatively compared key characteristics of the KCR and GCR. These characteristics included population served, size of the coverage area, number of data sources, data collection approach, and whether the catchment area had a cancer referral center, all factors previously shown to impact the cost of registry operations [12]. Using the differences in these factors, we identified whether the cost of specific GCR operations was likely to be lower, higher, or the same as the KCR. We also identified a list of activities and potential sources of monetary and non-monetary contributions to sustain the GCR operations in the future.

4. Results

4.1. Kampala and Gulu Cancer Registry characteristics

Table 1 summarizes the key characteristics of the KCR and GCR. The population served by the GCR, about 756,547, is a little less than 30% of the population of the Kampala registration area, but the area covered is about six times larger, about 11,820 square kilometers across three Ugandan districts [16]. With a smaller population over a much larger geographic area, the GCR's population density is 64 persons per square kilometer, which is a contrast to KCR's 1374 persons per square kilometer. While Kampala uses a combination of passive and active approaches to collect data, the GCR relies on active data capture to collect information from Lacor Hospital and five other facilities in the Amuru and Nwoya Districts. Kampala has more data sources than Gulu and is also home to a major referral cancer treatment hospital. As shown in Table 1, the GCR serves a smaller population and has fewer data sources; these factors lessen the effort required to collect data.

4.2. Kampala Cancer Registry Data Quality

Since its inception, the KCR has instituted mechanisms for ensuring high quality data. These mechanisms include continuous retraining of its registrars on data collection methods and processing. Furthermore, the registry undertakes completeness

Table 1
Kampala and Gulu Cancer Registry Characteristics.

	Kampala	Gulu
Population served[1]	2,629,132	756,547
Area covered (sq. km)	1914	11,820
Population Density (person per sq. km)	1374	64
Data collection method	Passive and active	Active
Number of data sources	18	6
Incident Cases[2]	1907	328
Cancer referral hospital	Yes	No

Notes: [1]Kampala Cancer Registry population served and area covered includes Kyadondo County while the Gulu Cancer Registry population served and area covered include the Ugandan districts of Amuru, Gulu, and Nwoya. Gulu population and area covered Source: Uganda Bureau of Statistics. [2]Incident cases for Kampala correspond to those diagnosed during 2012; Gulu incident cases correspond to the annual average from 2013 to 2014.

assessments of the cancer cases by using a large case series collected independently of the cancer registry mechanisms. The completeness of registration using this approach was assessed as 90%, indicating a generally high level of accuracy in the incidence rates reported by the registry [17]. Another method used to determine quality is matching studies, such as the Uganda AIDS-Cancer Registry Match study [8]. The matching process indicated that the KCR was able to provide good quality variables for the linkage process and for the identification of specific cancer sites. KCR data have been included in *Cancer Incidence in Five Continents* (CI5) continuously since the 1990s due to the registry's rigorous quality assessment approach to ensure high quality data. Results from the KCR have been published in volumes VII (1991–1993), VIII (1993–1997), IX (1998–2002), and X (2003–2007) of CI5.

4.3. Kampala and Gulu Cancer Registry Cancer Incidence

Table 2 shows the top five age-standardized incidence rates for Gulu in 2013–2014 compared with those in Kampala in 2008–2012. Overall, Gulu age-standardized incidence rates are lower than the rates for Kampala, although the incidence of cancer of the cervix is higher. In part, this difference in rates reflects the more rural nature of the population in Gulu. The incidence of childhood Burkitt lymphoma is also higher in Gulu than in Kampala [9].

4.4. Cost of operating the Kampala Cancer Registry

The main sources of support for the KCR were the host institution (Makerere University), the International Network for Cancer Treatment and Research (INCTR), and the International Agency for Research on Cancer (IARC). The host institution, which provided 58% of KCR's total resources, contributed through direct transfers (e.g., salary for one of the registrars) and through other contributions, such as use of facilities, provision of services (e.g., administration, IT support, and transportation), equipment (e.g., computers and printers), and furniture. International organizations, which included INCTR and IARC, contributed 42% of KCR's resources.

Fig. 2 presents the cost distribution of the KCR by the standard budget categories of labor, travel, training, equipment and materials, and administrative costs. More than half of the costs were related to registry staff salaries and other labor compensation (59%), and 12% were for administrative support related to registry space, information technology, and utilities. Equipment and materials, such as office supplies, hardware, and printing, accounted for 15% of the registry's costs. Travel and training-oriented non-labor payments were 8% and 6% of the total costs, respectively. The KCR, at least during the annual period studied, expended a significant portion of its resources on training staff at other registries, especially GCR staff. This training is reflected as a cost to the KCR, when in fact the training benefits other registries.

Fig. 3 provides the details on spending by registry activity categorized into the broad components of fixed cost, variable core cost, and variable other cost activities. These detailed activity-based costs take into account the percentage of staff time spent on each activity. Overall, the highest cost activities were administration and indirect costs, followed by data collection and abstraction. Among the fixed cost activities, administration and management made up 83% of the cost, and training of registry staff made up another 8% (not shown in figure). Within the variable core cost category, 78% of the cost was for data collection, abstraction, and entry into the registry database (not shown in figure). Case consolidation, quality assurance, and sharing of cases accounted for the remaining variable core costs. The KCR performed several variable other cost activities. The highest cost was allocated to training of others by the registry (which is overall the third highest cost activity). Other activities included publications, activity follow up, and research studies. In terms of cost per cancer case, fixed costs were 11,736 Ugandan Shillings (UGX), variable core costs were 11,303 UGX, and variable other costs were 5162 UGX (4.25, 4.09, and 1.87 respectively in 2014 US dollars). The total cost of the KCR during 2014 was about 53.7 million UGX, which was equivalent to a little less than 20,000 US dollars in 2014.

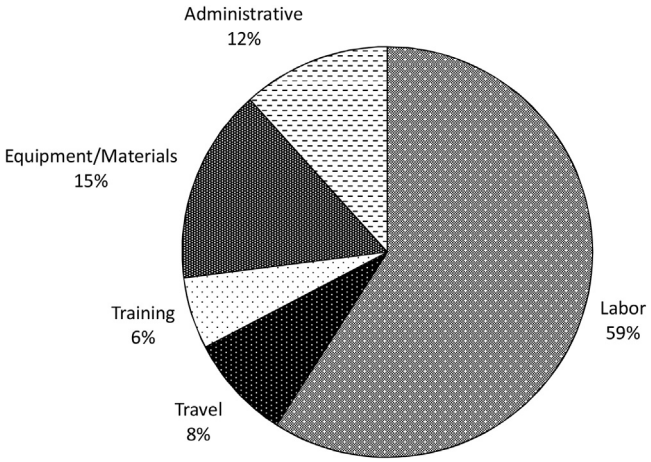

Fig. 2. Kampala Cancer Registry Costs by Budget Category, 2014.

4.5. Extrapolating resources required to sustain cancer registration in Gulu

The GCR is a start-up registry; however, as shown in Table 3, the registry will likely require stable and continued funding support to sustain operations in the future, as current funding is from a research study. Covering a larger geographic area may increase costs for the GCR; the staff need to travel to several other major hospitals in the coverage area, and the furthest hospital requires a trip of some 100 kilometers. Overall, we anticipate that the cost of equipment and administration may remain relatively the same for both registries. Currently, all the GCR start-up operations are

Table 2
Age Standardized Incidence (per 100,000) and Number of Cases, for the Five Major Cancers of Each Sex in Gulu (2013–14), and Kampala (2008–12).

Male			Female		
Cancer	Gulu ASR (No.)	Kampala ASR (No.)	Cancer	Gulu ASR (No.)	Kampala ASR (No.)
Prostate	14.5 (46)	49.5 (515)	Cervix uteri	53.3 (203)	51.1 (1057)
Kaposi sarcoma	8.9 (48)	25.2 (911)	Breast	11.6 (41)	30.6 (619)
Liver	7.9 (35)	10.0 (201)	Liver	5.3 (18)	8.4 (163)
Oesophagus	5.4 (17)	22.9 (284)	Non-Hodgkin lymphoma	4.3 (25)	5.6 (201)
Non-Hodgkin lymphoma	4.8 (29)	7.3 (255)	Kaposi sarcoma	3.6 (22)	14.8 (651)

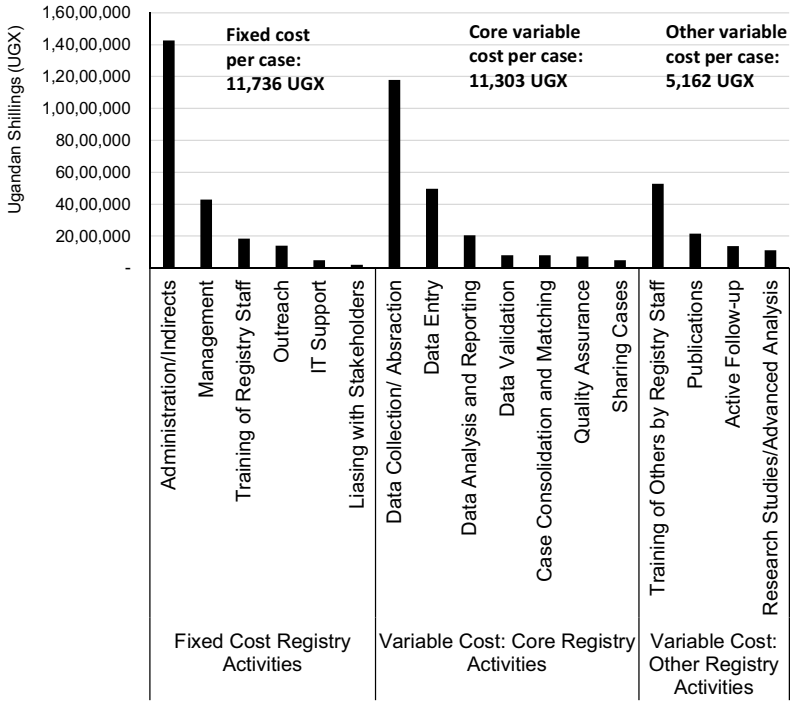

Fig. 3. Kampala Cancer Registry Costs by Activity, 2014.

Table 3
Potential Sources of Non-Monetary and Monetary Contributions and Comparative Resources Needed to Sustain the Gulu Registry.

	Host Institution	External Funding	Other Support	Kampala Versus Gulu[1]
Start-Up Costs				
1) Planning for registry data collection approach	✓		✓	Gulu registry has developed standard operating policies and is currently fully supported by the host institution in its start-up activities
2) Hiring of staff members	✓			
3) Training of registry and other staff	✓		✓	
4) Equipment (e.g., computers and printers), furniture, and office space	✓			
Recurrent Costs				
1) Staff salaries (number and training)	✓	✓		Lower staff hours due to fewer cases but active method and travel will require more effort; so overall anticipate slightly lower or similar cost for Gulu compared to Kampala
2) Travel expenses for data collection	✓	✓		Higher for Gulu compared to Kampala due to larger distance between data sources
3) Office supplies and software	✓	✓	✓	Similar cost
4) Indirect cost (e.g., for utilities)	✓			Similar cost

Note: [1]These findings are based on qualitative discussions with registry staff as well as cancer registration experts.

supported by the host institution with assistance from international agencies, such as the IARC, in terms of technical expertise as well as free cancer registry software.

5. Discussion

Estimation of cancer incidence, mortality, and prevalence in Uganda is currently based only on the results from the Kampala cancer registry [18]. This is clearly unsatisfactory, given the size and diversity of the country. Although a national cancer registry seems an ideal solution, this has proved impossible to achieve in Africa for countries with populations greater that 1–2 million. The IARC recommends that, given the prohibitive costs involved, that most of the requirements for planning and monitoring can be achieved through registration of a subset (sample) of the national population, using one or more regional population-based cancer registries [19]. This model is being adopted in Uganda. The first regional registry is being established in Gulu, and a second is in the planning phase in Jinja in Eastern Uganda.

The economic evaluation of the KCR operations indicates that the cost of collecting and reporting data for one cancer case is about US $10 in 2014. This is very favorable compared with the much-higher costs incurred in high-income countries [20,21]; the average cost per case for the registries funded by the CDC in the United States is about US $61 [22]. In the KCR, about 40% of the costs are devoted to fixed cost activities, and the remaining 60% to variable cost activities; therefore, substantial fixed costs will be incurred regardless of the volume of cases collected. Almost 60% of the contribution required to sustain operations of the KCR comes from the host institution, Makerere University. This institutional support provides stability needed for sustaining long-term operations, although it would not be adequate to maintain registry

operations without contributions from external donors. Altogether, the KCR has two full-time staff (one is a university employee receiving a low salary) and one part-time principal investigator which served 2.6 million inhabitants in 2015.

There are many differences between the registries; some of these differences increase the cost of operations, and others decrease it. Future assessments need to use time-and-motion or other similar techniques to get a more-accurate assessment of the resources needed for the variable core cost activities. Given that the GCR is new and is located in a rural area, it will likely require fewer resources than the KCR. The current start-up registry operations at Gulu are supported by Lacor Hospital and research funding from the INCTR, and continued support from the host institution are needed to cover registry overhead costs.

The KCR has some unique strengths that may be difficult to replicate, at least immediately, in other settings. The small team of dedicated staff have worked collaboratively for a long period of time, which helped them acquire the skill set for performing registry activities, and develop institutional knowledge. The dedication of the registry staff is a key strength of the KCR and is invaluable in ensuring the quality of cancer registry data. Therefore, a limitation of the extrapolation exercise that needs to be highlighted is that the quality achieved in the KCR may not be feasible in other newly established registries without substantial training. Some of the expertise may have to be gained through hands-on experience, which takes time. Although we attempted to capture all the costs involved in training there may be specific payments made directly to individuals that may be underreported. Lastly, although we used standardized definitions to assign activity-based costs and provided ongoing technical assistance, there could have been misallocations of resources among the registry activities.

6. Conclusions

Our study demonstrates the utility of using cost data collected from a well-established urban cancer registry to assess the resources required to operate a new registry in a rural area. This approach might become increasingly important as demand for representative cancer surveillance data among diverse populations increases in limited-resource settings. As shown in the comparison between KCR and GCR, some factors increase the cost of operations, and others decrease it. Our best estimate is that the GCR should require fewer resources than the KCR to sustain operations as a stand-alone entity. An in-depth assessment of the data collection process (such as using time and motion analysis) at each registry is necessary to more accurately estimate the resources required for cancer registration. The KCR is a well-established registry that produces high-quality data and has several unique strengths. Therefore, the costs incurred by the KCR may not be completely generalizable. Nevertheless, they provide an overall framework and guidance on the resources required to sustain population-based cancer registries in the resource-limited setting.

Author contributions

Henry Wabinga: Lead author; manuscript conception and design; interpretation of data; drafted the manuscript; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Sujha Subramanian: Co-author; manuscript conception and design; acquisition, analysis, and interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Sarah Nambooze: Co-author; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Phoebe Mary Amulen: Co-author; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Patrick Edwards: Co-author; acquisition, analysis, and interpretation of data; table/figure creation; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Rachael Joseph: Co-author; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Marin Ogwang: Co-author; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Francis Okongo: Co-author; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Maxwell Parkin: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Florence Tangka: Co-author; manuscript conception and design; acquisition, analysis, and interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

The findings and conclusions in this manuscript are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Conflicts of interest

None.

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