2020 NPCR PUERTO RICO CENTRAL CANCER REGISTRY SUCCESS STORY

STORY TOPIC: Challenges in Registry Operations after Hurricane Maria

STORY CATEGORY: Registry Operations

STORY TITLE: Adjustment to Completeness Estimates after a Natural Disaster: The Puerto Rico Experience after Hurricane Maria

STORY AUTHORS: Zavala D., Tortolero G., Centeno O., Torres C., Roman Y., Santiago Y., Vazquez N., Arce J., Alvarado M., Ortiz, K.

SUMMARY

Given the significant impact of hurricane Maria and the ongoing changes in population size and structure in Puerto Rico (PR), the Puerto Rico Central Cancer Registry (PRCCR) proposed adjustments to the completeness estimates methodology used by the National Program of Cancer Registries (NPCR) and the North American Association of Central Cancer Registries (NAACCR) for Puerto Rico 2017 data.

CHALLENGE

On September 20, 2017 hurricane Maria crossed Puerto Rico from southeast to northwest. There were over 9 hours of sustained category 4 (155 mph) hurricane winds leading to catastrophic damage of its infrastructure. A total collapse of the electronic grid left the entire population without electricity. In large areas of PR, the lack of electric service extended for months. Services on medical offices and hospitals were limited for at least 2 months. All laboratories and medical facilities decreased substantially their workload and some small and medium hospitals closed temporarily. Cancer diagnosis and treatment procedures were delayed due to lack of access to medical services. Medical services started to operate normally by late December 2017.

Before hurricane Maria impacted Puerto Rico, the island was already experiencing a decrease in population size since the 2010 census.[1] According to a report released by the U.S. Census Bureau on September 26, 2019,[2] an estimated 142,000 people (4.4% of the population) left the island in the aftermath of Hurricane Maria. Approximately 133,500 people migrated from the island to the mainland United States in 2018, a 36.9% increase from the previous year.[3] Given these circumstances, the PRCCR proposed adjustments in the methodology used by NPCR and NAACCR in their completeness estimates for Puerto Rico for 2017 data.

SOLUTION

A detailed evaluation of pathology reports and reported cases before and after the hurricane Maria confirmed that there was a general reduction of cancer diagnoses since September 20,

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[1] https://www.census.gov/quickfacts/PR

[2] A third of movers from Puerto Rico to the Mainland United States Relocated to Florida in 2018. http://tiny.cc/np8qdz

[3] Glassman B. More Puerto Ricans move to Mainland United States, Poverty Declines. US Census Bureau. September 26,2019 https://census.gov/library/stories/2019/09/puerto-rico-outmigration-increases-poverty-declines.html?utm_campaign=20190926msacos3ccstors&utm_medium=email&utm_source=govdelivery

2017 in all reporting sources including hospitals, laboratories, and other medical facilities. Based on this observation, the PRCCR proposed two models to adjust completeness estimates using the first eight months of 2017 only, and using the primary sites used by NAACCR completeness methodology.

PRCCR analysis showed that the 2017 data had nearly 3% of cases with unknown month of diagnosis. These cases were factored in both proposed models. The first model uses a 'correction factor' which is calculated based on data for the years 2010 to 2016 and includes the number of cases with unknown month of diagnosis redistributed into the first eight months of each year. Using the average of the differences between all cases (including cases without month known) and all cases excluding cases without month known. This average is then subtracted from 100 and divided by 100 to obtain a proportion (0.9783) which is the correction factor applied to the NAACCR worksheet for Completeness of Case Ascertainment version 2.2.b. The second model uses four different strategies to select the cases with unknown month and day of diagnosis. The second model uses an algorithm to select 2/3 (eight months of 2017) of the cases with unknown month.

RESULTS

The PRCCR proposed two models for the adjustment of the completeness estimate for 2017. In both models the completeness is based on the number of cases registered in the first eight months of 2017 only.

The first model estimated completeness (%) is slightly higher than NAACCR's official completeness estimate (twelve months). Detailed results of Model 1 are shown in Appendix 1a. One issue with model 1 is that the correction factor includes all cases with unknown month of diagnosis, it does not exclude cases with a primary site that are not included in NAACCR'S completeness calculation. Model 2 is an attempt to adjust further the completeness estimate by randomly assigning eligible cases used in the completeness estimate in a 3:1 ratio for the first period (first 8 months of the year, January-August) and second period (last four months of the year, September-December). Model 2 does not require a correction factor as it distributes the cases with unknown month of diagnosis of eligible cancer cases for completeness in a randomly fashion in the first and second period of each year. Detailed results of Model 2 are shown in Appendix 1b.

Both models were tested comparing a recalculated NAACCR's completeness from 2010 to 2016 using the Vintage 2018 population with the model results for each year. The results of the adjusted completeness estimates based on the first 8 months using Model 1 and Model 2 compared to NAACCR's official estimates are shown in the table below. Both models provide close estimates to NAACCR actual completeness estimates for the period 2010 to 2016 and therefore could be applied to 2017 completeness estimate.

	2010	2011	2012	2013	2014	2015	2016
NAACCR Completeness %	89.1	91.3	92.3	94.0	95.3	96.7	94.2
Model 1 estimates %	88.2	89.7	92.8	94.8	97.4	96.5	94.1
Model 2 estimates %	88.5	90.3	93.6	95.2	97.8	97.2	94.5

SUSTAINING SUCCESS

Adjustments to calculate completeness are needed when cancer registry operations are interrupted or altered by catastrophic events like hurricanes, earthquakes, and other natural disasters. The PRCCR proposed to both, NPCR and NAACCR to consider the suggested models for adjustment to the completeness estimates for Puerto Rico 2017 data. Both institutions took into consideration these findings and provided adjusted completeness estimates using data from the first six months of 2017 as it did in 2005 with the Louisiana Cancer Registry after hurricane Katrina.

The PRCCR was able to achieve NAACCR Gold Certification for 2017 data and remain qualified for inclusion in US Cancer Statistics and other important venues for sharing critical information on cancer incidence and mortality.

REGISTRY CONTACT INFORMATION

787-772-8300 ext. 1100
www.rcpr.org