



Implementing the Health Information National Trends Survey in Puerto Rico (HINTS-PR): Partnership, Lessons Learned, and Preliminary Findings



How Americans find and use cancer information

Health Information National Trends Survey



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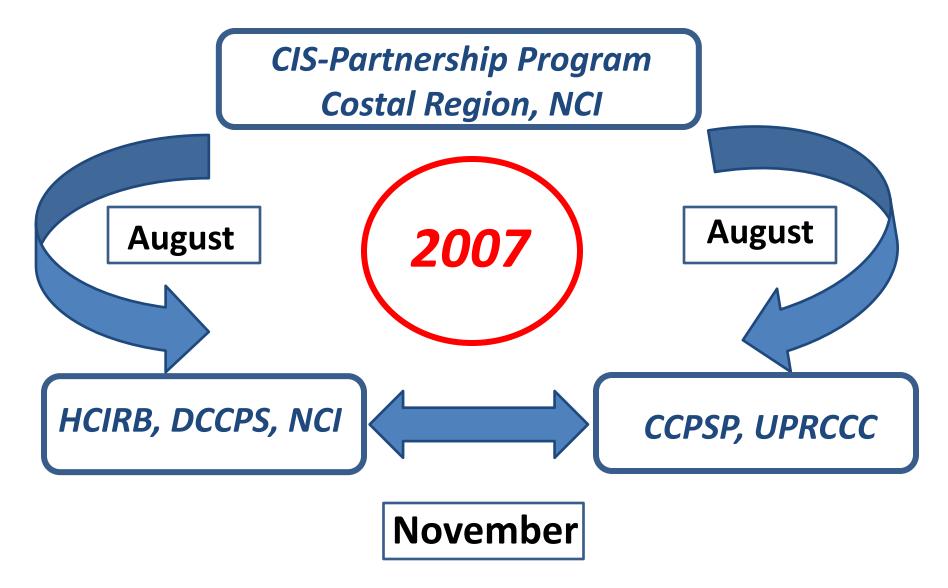
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Expanding HINTS: *University of Puerto Rico Comprehensive Cancer Center*



HINTS-Puerto Rico

HINTS-Puerto Rico Partnership



HINTS-PR Objective

 Conduct HINTS 2007 among a random sample of the adult population (age 18+ years) of Puerto Rico to extend our understanding of the information needs, cancer-related knowledge, and behavior of Hispanic populations

 Lend insight into the sharing of survey resources on a population outside the continental U.S., and particularly to Spanish speaking population

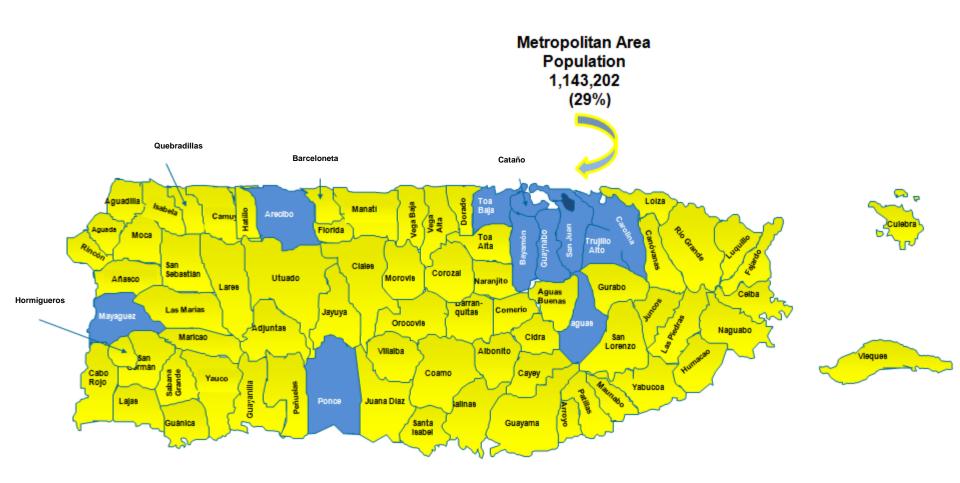
HINTS-Puerto Rico Partnership

- April, 2008: Start process for collaboration
 - HCIRB and UPRCCC
- June, 2008: Meeting HCIRB, Westat, CIS, PR-BRFSS and UPRCCC
- October, 2008: HCIRB/UPRCCC contract Agreement completed
- October, 2008: Contract Agreement with Puerto Rico Department of Health

Puerto Rico: Socio-Political Context and Cancer Burden

Socio-Political Context Puerto Rico

- Commonwealth territory of the USA (1898)
- Island Population 3,949,000 (July 2003 est.)
 - Similar number living in Continental US
 - States with the largest Puerto Rican populations:
 Connecticut; New York; New Jersey; Massachusetts;
 and Florida
- Capital City: San Juan (n = 434,000)
- Languages: Spanish, English



42% of the population (n = 1,662,787) resides in 11 counties

Map of Puerto Rico by municipalities (n = 78)

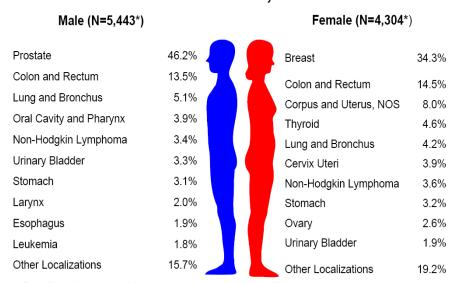
Demographic Characteristics: Puerto Rico

- Median age 34.9 years
 - 65+ years = 13 %
- Median household income: \$18,191
- Population Below Poverty Level: 45%
- Education (25+ years):
 - O 66% had ≥HS
 - 21% Bachelor's or higher degree
- Hispanics = 99%
- Native Puerto Rican = 97%
- Spanish speakers = 95%

Cancer Burden in Puerto Rico

Cancer is the second leading cause of death in Puerto Rico 16.6% of all deaths in 2004 (Puerto Rico Department of Health)

Top Ten Cancer Sites Puerto Rico, 2003



*Cases with age unknown were included.

Statistics were generated from malignant cases only

Source: Puerto Rico Central Cancer Registry, Puerto Rico Cancer Incidence File (May 2007), Division of Epidemiology, Puerto Rico

Department of Health.

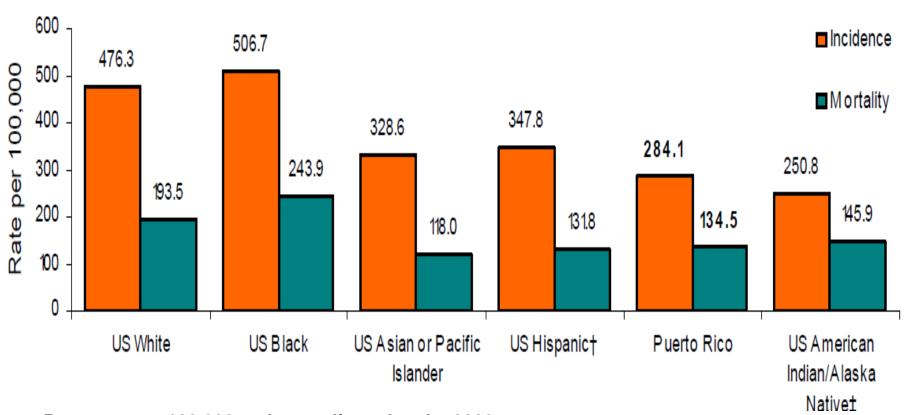
Top Ten Cancer Deaths Puerto Rico, 2004

Male (2,721*)		Female (N=2,105*)		
18.9%		Breast	19.7%	
14.3%		Colon and Rectum	13.3%	
13.0%		Lung and Bronchus	10.8%	
7.1%		Stomach	5.4%	
6.3%		Liver and Intrahepatic Bile Duct	5.2%	
4.2%		Pancreas	5.1%	
4.1%		Ovary	4.5%	
3.7%		Corpus and Uterus, NOS	4.0%	
3.5%		Non-Hodgkin Lymphoma	3.5%	
3.1%		Leukemia	3.5%	
21.8%		Other Localizations	25.0%	
	14.3% 13.0% 7.1% 6.3% 4.2% 4.1% 3.7% 3.5% 3.1%	14.3% 13.0% 7.1% 6.3% 4.2% 4.1% 3.7% 3.5% 3.1%	Breast Colon and Rectum Lung and Bronchus Stomach Liver and Intrahepatic Bile Duct Pancreas Ovary Corpus and Uterus, NOS Non-Hodgkin Lymphoma Leukemia	

*Deaths with age unknown were included.

Source: Puerlo Rico Central Cancer Registry, Puerto Rico Mortality File (released August 2006), provided by the Division of Statistical Analysis, Auxiliary Secretariat for Planning and Development, Puerto Rico Department of Health.

All Sites Cancer Incidence and Death Rates* by Race and Ethnicity, PR and US², 1999-2003



Rates are per 100,000 and age-adjusted to the 2000 US standard populat ion

Figueroa NR, De la Torre T, Ortiz KJ, Pérez J, Torres M (eds). All Sites Cancer Stat Fact Sheet, Puerto Rico Central Cancer Registry. San Juan, PR, http://www.salud.gov.pr/RCancer/Reports/Pages/default.aspx, based on May 2007 Puerto Rico Central Cancer Registry data submission, posted on the Puerto Rico Department of Health web site, 2008.





HINTS-Puerto Rico Survey Plan

- Use the existing Puerto Rico-Behavioral Risk Factor Surveillance System (PR-BRFSS) infrastructure to conduct HINTS in Puerto Rico
- Puerto Rico-BRFSS (PR-BRFSS) has been part of the Puerto Rico Department of Health, Epidemiology and Research Office since 1995
- The PR-BRFSS staff in 2008 consisted of eleven Interviewers, an Administrator, a Secretary and the Director/Coordinator. They devote 100% of their time effort to Puerto Rico BRFSS activities
- PR-BRFSS conducts surveys in English and Spanish
- PR-BRFSS response rate is **72.6**% (2005)

- The University of Puerto Rico Cancer Center (UPRCC) sub-contracted with PR-BRFSS to conduct the survey
- Spanish version of HINTS 2007-2008 Survey
- Survey reviewed by Puerto Rican team for language appropriateness and need for adaptation of survey items
 - "Health Reform" was added to the statement of question related health insurance
 - "Place of birth" was modified (options included Puerto Rico; Continental US; and Other)

- In addition, all response options and instruction for the interviewers were translated to Spanish
 - Facilitate data collection in Puerto Rico
 - Future implementations of HINTS in other Hispanic/Latin American populations inside and outside the US
- Pilot test the revised instrument in a sample of 20 subjects (10 females/10 males) by PR-BRFSS using a paper format
 - To identify any major issues related to the appropriateness of the Spanish translation for the Puerto Rican population

- Implementation of data collection instrument into CATI by Westat: April, 2009
- Training to the Puerto Rico-BRFSS by Westat staff (3-day): April, 2009
 - Review of interview procedures
 - Hands-on training at PR-BRFSS telephone center
- Data collection: April 27- June 30, 2009
- Data cleaning and weighting: July-August, 2009

Sampling Procedures

- Disproportionately stratified sample of phone numbers in Puerto Rico (Genesys)
- Sampling strata: 8 geographic regions used as sampling strata for the BRFSS program
- Westat managed sample and provided weekly list of telephone numbers to PR-BRFSS staff

Management of the data collection

Westat Telephone Research Center and the PR-BRFSS telephone center



HINTS/PR Wrap –Up Meeting September1-2, 2009













Preliminary Findings

Preliminary Findings

- Preliminary descriptive analysis of population estimates of:
 - 1) Health information seeking
 - 2) Sources of Health information
 - 3) Cancer information seeking
 - 4) Sources of cancer information
 - 5) Internet use
 - 6) Type of internet access

Table 1
Sociodemographic Characteristics: HINTS Puerto Rico

	Counts PR (n=639)	Weighted Percentages PR
GENDER Male Female	189 450	46.3 53.7
AGE GROUP 18-34 35-49 50-64 65-79 80+	81 115 194 192 57	31.9 27.9 21.4 13.9 4.8
EDUCATION Less than High School High School Graduate Some College/Vocational College Graduate or Beyond	170 147 121 162	24.0 27.8 27.9 20.3
HISPANIC Yes No Missing	595 8 36	98.7 1.3 -
PLACE OF BIRTH Puerto Rico US mainland Other Missing	571 18 14 36	94.7 3.0 2.0 -

Health Information Seeking

- Ever Seeking Health Information: <u>32.9%</u> (n=219)
- Sources of Health Information the most recent time looked:

7.9%
,

- Printed media 29.4%

Health Care Professional 9.8%

- Other 2.9%

Table 2
Health Information Seeking and Sociodemographic Characteristics:
HINTS Puerto Rico

Ever Seeking Health Information	Yes (n=219)	Weighted Percentage
GENDER Male Female	52 167	22.6 41.8
AGE GROUP 18-34 35-49 50-64 65-79 80+	35 53 75 47 9	39.6 33.5 34.6 21.6 10.6
EDUCATION Less than High School High School Graduate Vocational College Graduate or Beyond	23 35 54 94	15.1 21.9 41.0 56.4

Table 3
Main Source Health Information the Most Recent Time
By Sociodemographic Characteristics:
HINTS Puerto Rico

Source of Health Information	Internet wt%	Printed wt%	Health Care Professional wt%	Other wt%
GENDER Male Female	63.6	22.0	12.2	2.2
	55.3	32.9	8.7	3.2
AGE GROUP 18-34 35-49 50-64 65-79 80+	79.9	11.0	8.3	0.9
	65.7	24.1	7.1	3.1
	31.7	54.2	14.9	0.8
	15.9	53.1	14.9	16.1
	0	84.5	15.5	0
EDUCATION Less than HS HS Graduate Some College/Vocational College Graduate or Beyond	0	64.1	29.4	6.5
	63.2	26.3	8.6	1.9
	57.3	34.7	7.0	1.0
	75.1	15.4	4.9	4.6

Cancer Information Seeking

- Ever Seeking Cancer Information: 28.1% (n=181)
- Sources of Cancer Information the most recent time looked:

Internet	49.9%

Printed media 29.7%

Health Care Professional 14.7%

- *Other* 5.7%

Table 4
Cancer Information Seeking and Sociodemographic Characteristics:
HINTS Puerto Rico

Ever Seeking Cancer Information	Yes (n=181)	Weighted Percentage
GENDER Male Female	41 140	20.7 34.5
AGE GROUP 18-34 35-49 50-64 65-79 80+	26 52 55 38 109	31.6 35.4 23.9 17.2 13.0
EDUCATION Less than High School High School Graduate Vocational College Graduate or Beyond	19 27 49 77	11.9 16.7 43.3 41.1

Table 5
Main Source of Cancer Information the Most Recent Time
By Sociodemographic Characteristics:
HINTS Puerto Rico

Source of Health Information	Internet wt%	Printed wt%	Health Care Professional wt%	Other wt%
GENDER Male Female	50.3	30.4	15.7	3.6
	49.7	29.4	14.1	6.7
AGE GROUP 18-34 35-49 50-64 65-79 80+	71.4	9.1	18.9	0.7
	51.8	27.8	5.7	14.7
	27.5	58.5	12.9	1.1
	15.0	46.0	28.7	10.3
	0	78.1	19.1	2.9
EDUCATION Less than HS HS Graduate Some College/Vocational College Graduate or Beyond	1.2	56.6	25.1	17.0
	59.1	28.4	2.1	10.5
	46.8	30.7	19.5	3.1
	67.0	20.4	10.0	2.7

Internet Use

 Do you ever go on-line to access the Internet or World Wide Web to send and receive e-mail?:

• Type of Internet Access:

	DCI	Madam	26 00/
_	DSL	Modem	36.9%

Table 6
Internet Use and Sociodemographic Characteristics:
HINTS Puerto Rico

Access to Internet	Yes (n=142)	Weighted Percentage
GENDER Male Female	52 90	30.7 35.1
AGE GROUP 18-34 35-49 50-64 65-79 80+	47 51 28 15 1	58.1 37.0 13.5 6.2 1.7
EDUCATION Less than High School High School Graduate Vocational College Graduate or Beyond	1 13 41 81	1.5 23.8 50.0 59.3

Conclusions

- This is an example of collaboration among the HCIRB and CIS (NCI), UPRCCC, and the PR-BRFSS, Puerto Rico Department of Health
- The collaboration with the PR-BRFSS provided access to:
 - Trained and experienced staff conducting telephone computer-assisted surveys
 - Bilingual interviewers
 - Culturally appropriate interviewers

Conclusions

- HINTS-Puerto Rico provides an opportunity to increase our knowledge of the information needs, cancer-related knowledge, and behavior of Hispanic populations, and of the Puerto Rican population
- HINTS data will play a critical role in cancer control planning in Puerto Rico
- HINTS data will complement existing health-related data sources

Conclusions

- This collaboration provides insight into the sharing of survey resources on a population outside the continental U.S.
- Feasible to conduct HINTS outside the continental U.S.
 - Required small amount of resources and time
- Provides a model for conducting HINTS in other
 Spanish speaking countries and other US Territories
 with similar resources (e.g.; BRFSS)

Future Plans

- Dissemination od Data:
 - Briefs
 - Facts Sheets
 - Supplements
 - Reports
 - Manuscript
 - Other dissemination tools
 - Internet
 - Partners
- Data Release Estimated date: Fall, 2010
- Identify resources to continue HINTS-PR