CANCER REPORTING IN ST. JOHN PARISH

CANCER SURVEILLANCE PROJECT

Final Report 2021

LSU Health NEW ORLEANS
School of Public Health

Contents

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Executive Summary

Between January 2020 and January 2021, the Cancer Reporting In St. John Parish (CRISP) project was conducted by the School of Public Health, LSU Health Sciences Center to address concerns regarding cancer occurrences associated with proximity to the Denka Performance Elastomer facility, formerly DuPont facility, in St. John the Baptist Parish. The main objective of this project was to verify the completeness of cancer reporting in St. John Parish.

For the project, all the residents in the 2.5-kilometer radius around the Denka Facility were approached to participate in the survey. The aim of the project was to identify at least 10% of all cancer cases diagnosed between 2009 and 2018 in the survey area and link resident-reported cancer cases to records in the LTR database. In addition to cancer cases, the residents were able to report any health conditions and/or community concerns about living near the Denka facility.

For the project, we expected to approach all 1,821 households through door-to-door surveying, however due to the COVID-19 pandemic, door-to-door surveying had to be suspended and surveys were conducted by phone interviewing. A multipronged approach was used to contact residents in the survey area which included purchasing a phone registry, mailing out flyers to residences in the survey area, and contacting businesses and community organizations around the Denka facility.

The CRISP project was concluded with 179 households participating in the survey, of which 83 households reported at least one cancer case and 96 households where no cancer was reported. There were 141 resident-reported cancer cases that were reviewed. For the time period of 2009-2018, 50 reportable cancers were identified and verified in the LTR database. **No reportable cancers were identified that were not a part of LTR data** (additional information can be found in Table 2 and Appendix Section C – Figure 2).

In addition to cancer information collected, many residents voiced concerns about other issues related to plant emissions including the relationship to other health conditions, and the effect on children's health in the area. **The CRISP review and confirmation of cancers in St John parish can neither confirm nor refute any links between exposures to chemicals and cancer or other disease occurrences.**

Background

The Cancer Reporting In St. John Parish (CRISP) project was conducted by the School of Public Health, LSU Health Sciences Center New Orleans in cooperation with the Louisiana Department of Health to address concerns regarding cancer reporting and occurences associated with exposure and proximity to the Denka Performance Elastomer facility, formerly DuPont facility, in St. John the Baptist Parish. In March 2018, the University Network for Human Rights (UNHR) organization surveyed a sample of residents in a 2.5-kilometer radius around the Denka facility and released an executive summary report entitled "Waiting to Die: Toxic Emissions and Disease Near the Louisiana Denka / DuPont Plant" [1,2]. Due to the reporting of increased cancer prevalence in "Waiting to Die," there is concern from the St. John Parish community that the Louisiana Tumor Registry (LTR) data is incomplete and therefore, the LTR-reported cancer incidence rates around the Denka facility on the census tract level are underestimated.

The primary source of information about Louisiana's cancer occurrence is the LTR, housed at LSU Health Sciences Center School of Public Health in New Orleans[3]. The LTR is funded by the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and the State of Louisiana and follows national guidelines to collect and report cancer cases occurring among Louisiana residents. The LTR participates in both the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute (NCI) and the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC)[5]. The NCI and CDC have extensive case reporting requirements that the LTR must follow. LTR must collect information on all reportable cancer cases (as defined by national standard setters) diagnosed in Louisiana and out-of-state healthcare facilities and make extensive efforts to retrieve any missing cancer cases through methods approved by the NCI and CDC[5,6].

The community of St. John Parish is concerned that the LTR data do not accurately reflect the cancer rates around the Denka facility in light of the UNHR report and also are concerned the closure of River Parishes Hospital (Laplace, La) in 2014 may also contribute to unreported cancer cases in parish residents.

The LTR has repeatedly received national recognition for case completeness and because the above mentioned report relies on self-reporting, this project will provide the community with the highest level of verification of LTR's cancer rates in their neighborhoods[4].

Louisiana Tumor Registry (LTR)

The Louisiana Tumor Registry (LTR), a statewide population-based cancer registry, compiles information to help guide policies and target interventions for cancer prevention to reduce the state's cancer burden and disparities and improve cancer patients' survival and quality of life. LTR data users include policymakers, cancer prevention programs, physicians and other medical practitioners, planning offices for

healthcare facilities, the public health community, and researchers. These groups rely on timely, complete, and high-quality data from the Registry. LTR has been recognized for its complete, high quality, and timely cancer data by national organizations. The LTR has received Gold Certificates from the North American Association of Central Cancer Registries every year since 1997, the first-place award from SEER every year since 2009 and has met all data quality standards for NPCR since 1998.

Purpose

The purpose of the Cancer Reporting in St. John Parish (CRISP) project is to verify the completeness of cancer reporting in St. John Parish. The goal is to approach all residents in the 2.5 km radius around the Denka Facility in order to identify at least 10% of all cancer cases diagnosed between 2009 and 2018 in the survey area and link resident-reported cancer cases to records in the LTR database. Specifically, this project aims to detect any missing reportable case in the survey area around the Denka facility for the 2009 to 2018 timeframe.

Rationale

The ten-year interval of 2009-2018 was selected for this project. The community has expressed interest in having all cancers reported since the establishment of the LTR reviewed. Cancer registries in the United States most commonly report cancer rates in five-year intervals. The five-year interval is less prone to sharp dips and peaks of annual reporting that can be related to changes in screening practices, for example, at the local level; the five-year interval is therefore considered the more accurate measure. Five-year intervals also lend themselves to comparisons across gender, race, and ethnic groups and state-to-state comparisons. **Reviewing all cancers since the establishment of the LTR would not contribute to currently reported cancer rates.** In addition, facilities are required by law to maintain records for ten years and therefore anything before 2009 cannot be verified. Therefore reviewing the most recent ten years of data will result in the review of as many records as possible, while ensuring the availability of source documentation and the usefulness of records reviewed.

Cancer incidence and mortality rates are the standard methods of measuring cancer rates in the United States. Cancer incidence rates are the number of people newly diagnosed with cancer within a specific population in a specified period. Prevalence, the measure of people living with cancer, is affected by many factors and it provides little information on cancer risk as it is affected not only by incidence but also survival. The survival time is not only related to cancer care but also cancer types. Cancers with over 90% 5-year survival rate, such as prostate, thyroid, testicular cancers, melanoma of the skin, will have a high prevalence whereas cancer with lower than 16% of 5-year survival rate, such as lung cancer, pancreatic cancer, esophageal cancers, will have a low prevalence. In addition, prevalence can be affected by access to cancer treatment which can vary from locale to locale, greatly impacting the pathologic stage at the time of diagnosis and survival. The longer a person survives, the higher the prevalence. In a

locality with better access to cancer diagnosis and treatment, residents would survive cancer for a longer time than in a community with poorer access. Therefore, a community with better access would have a higher prevalence.

Conversely, suppose people are diagnosed with cancer late in their disease. They would then not survive for a longer time, and the prevalence of cancer in that community would be lower than in a community with earlier diagnoses. Therefore, a high prevalence reflects both the incidence rate of cancer and the length of survival for all cases. For this reason, prevalence is not a preferred measure of cancer occurrence rates in a community.

Because the goal of this project is to verify the accuracy and completeness of LTR data through review of records and reports, it most closely represents the functions of an audit. The American Institute of Certified Public Accountants recommends as a basic rule of thumb a sample size of 10%. Therefore, this project began with the expectation of sampling at least 10% of the homes in the community of interest and reviewing at least 10% of the expected number of cancers for accuracy and completeness of reporting. Given approximately 1800 residences and a cancer case count of 656 within 2.5km radius of Denka Facility from 2003-2017. We divided this number by 15 to get an average annual count, and then multiplied this by 10, which resulted in 473 – the approximate number of cancer cases expected in a 10-year period.

With the expected number of cancers of 473, the project sought to verify at least 10% of all cancer cases, 47 reportable cancer cases, diagnosed between 2009 and 2018 in the survey area.

Methods

The implementation of the project involved surveying of residents in the 2.5 km radius around the Denka Facility. The survey area is the circle circumscribed within a 2.5 km radius of the Denka facility, the overall space the University Network for Human Right Group did for their study entitled "Toxic Emissions and Disease Near the Louisiana Denka/DuPont Plant." The estimated number of residences is 1,821. Addresses were obtained from the St. John the Baptist Parish Public Geoportal on the county website (https://atlas.geoportalmaps.com/stjohn_public/). The LSUHSC field workers went out into the survey area to collect responses from residents in the survey area and then the resident-reported information was sent for cancer diagnosis verification.

If a resident-reported cancer case was not found in the LTR database, staff investigated the case to determine if it is a reportable case through a medical record review from the healthcare facilities indicated by the resident on the survey. If the case was determined to be reportable and was not in the registry database, staff would manually abstract medical information for the case to be included in the LTR database. If it were determined that the case is a reportable case and was missed, LTR will report it as a missed case. LTR will identify how the case was missed and implement interventions to

prevent it from happening in the future. LTR will also abstract all missed cases and save them in the LTR database for future incidence rate reporting.

Due to the COVID-19 pandemic, the door-to-door surveying was suspended as of March 19, 2020. A multipronged approach was implemented instead of door-to-door surveying. Project flyers were mailed to all the residents obtained from the St. John Parish public geoportal. Phone registries were purchased for the survey area, and field workers contacted residents if they were interested in participating and completing a survey. Businesses and religious organizations in St. John Parish were contacted and sent project flyers to distribute to the congregation.

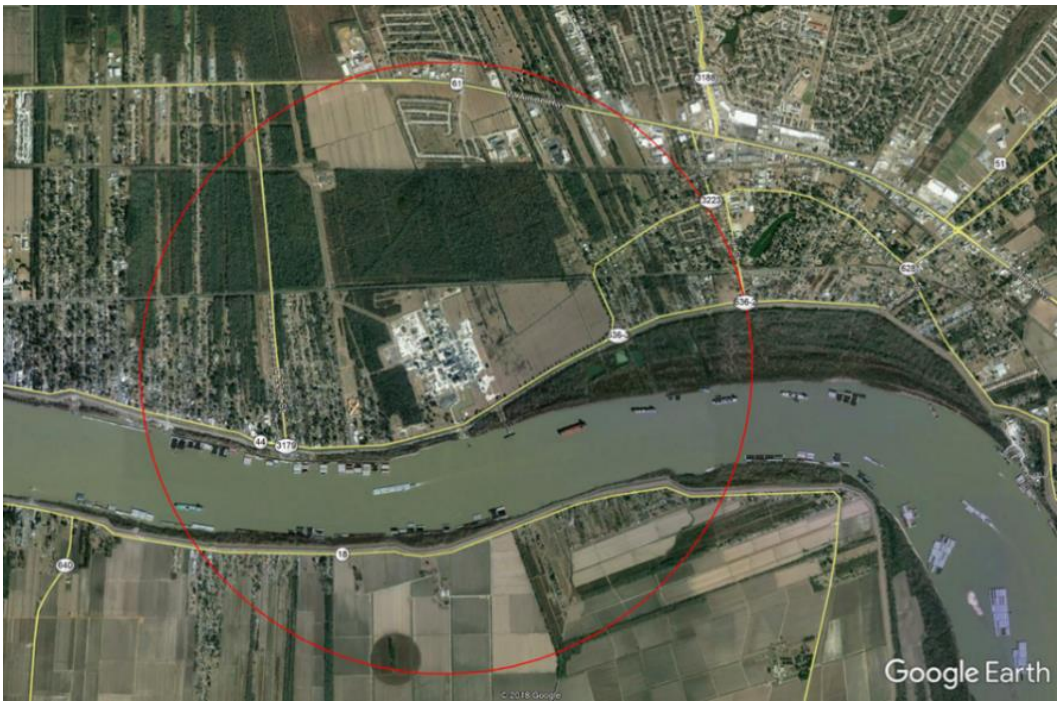


Figure 1:Image obtained from Google Earth of 2.5-kilometer survey area radius around the Denka Performance Elastomer facility in Laplace, La.

Survey Instrument

The forms of the survey instrument were developed based on information needed to identify and verify the cancer case, as well as input from the community during the town hall meeting on 11/5/2019. The survey instrument included 1) information of all the alive or deceased members of the household since 2009, 2) identifiers needed to verify the cancer case in the LTR database or access medical records, 3) health concerns, and 4) community concerns. The REDcap database was used to develop and administer the survey. The survey instrument was tested among project staff and field workers before the survey was placed into production mode on the REDcap database. Field workers used iPads to administer the survey while going around the survey area. After the suspension of door-to-door surveying on 3/19/2020 due to the COVID-19 pandemic, field workers used the web version of REDcap to administer surveys via telephone interviewing.

Training of Field Workers

All field workers attended a training session to review the background and aims of the project, receive a demonstration of administering the survey via REDcap, review possible questions and concerns of community members, and participate in role-playing scenarios. Once the field workers completed the training sessions, they practiced administering the survey via REDcap app on an iPad or via the REDcap website. Field workers that participated in door-to-door surveying went around the survey area to hand out the flyers and posters before the interviews started. The project had 3-4 field workers on the project surveying at a given time due to turnover.

Field workers started surveying west of the Denka facility starting from 31st Street in Reserve, LA then moving west towards 3rd Street. In the door-to-door canvassing, field workers traveled in pairs. They wore LSUHSC shirts with their LSUHSC ID cards while canvassing the survey area. They introduced themselves and explained the purpose of their visit. They only spoke to members of the household who were at least 21 years of age and were knowledgeable about each household member's health status. Once there was an agreement to participate, the interviewer completed the survey with the resident. If there were interruptions, the field workers decided whether to wait to complete the survey or rescheduled the interview in person or over the telephone.

Due to the suspension of door-to-door surveying on 3/19/2020, field workers continued with telephone interviews. Telephone interviews were conducted by using the Cisco Jabber app to call residents from LSUHSC phone lines and to administer the survey and document resident responses using the LSUHSC REDcap website.

Verification of resident-reported cancer cases.

The completeness of cancer cases was assessed by comparing resident-reported cancer cases with those in the LTR databases. Although the LTR would like to verify all resident-reported cancer cases regardless of the diagnosis years, there are limited resources and availability of medical records. The limited availability of medical records is due to healthcare facilities are only required to keep 10 years of records from present day and in St. John Parish, River Parishes Hospital closed in 2014 and it is recognized that records for cases diagnosed there may be unavailable. Each resident-reported cancer case was individually searched for in the LTR database using the identifiers provided by the resident during the survey. If additional information was needed to verify the cases, the field worker contacted the resident at least one additional time to attempt to obtain additional information needed.

For resident-reported cancer cases that are not in the LTR database, healthcare facilities were contacted based on information from the resident survey and access to their medical records was requested. These medical records were used to determine whether a resident-reported cancer occurrence is **a reportable case according to national standards of cancer reporting for the corresponding diagnosis year.** The list of reportable and non-reportable cancer diagnoses can be found in the Appendix.

IRB Review Exemption

Due to this project's nature as public health surveillance in conjunction with the LTR, this project is exempt from the patient consent provisions of HIPAA as the project falls under the 45 CFR 46.102(l)(2), which states the following:

> *"Public health surveillance activities, including the collection and testing of information or bio specimens, conducted, supported, requested, ordered, required, or authorized by a public health authority. Such activities are limited to those necessary to allow a public health authority to identify, monitor, assess, or investigate potential public health signals, onsets of disease outbreaks, or conditions of public health importance (including trends, signals, risk factors, patterns in diseases, or increases in injuries from using consumer products). Such activities include those associated with providing timely situational awareness and priority setting during an event or crisis that threatens public health (including natural or man-made disasters")" (45 CFR 46.102(l)(2)).”*

Confidentiality and Data Security

The legislation that established the Louisiana Tumor Registry (R.S. 40:1105.1 et seq.) protects health care facilities and providers that disclose confidential data in good faith to the LTR from damages arising from such disclosures. It also specifies that no confidential data shall be included in court proceedings of any type. The LTR shall establish procedures for the release of data and that all registry employees or other data users will sign confidentiality agreements. LTR data are encrypted from data entry through editing and consolidation procedures for as long as they are stored with the Registry. All encryption modules used to protect registry data have been validated by NIST to meet the currently applicable version of Federal Information Processing Standards (FIPS) 140-2.

Access to medical records

The Louisiana Tumor Registry legislative rules require health care providers and facilities to allow the Registry online access to medical records if electronic health records have been implemented (LAC 48:V.Chapter 85.8505.A). Remote access saves time for staff members from both the Registry and the medical institutions by facilitating, abstracting, editing, and obtaining enhanced data for special studies.

Community Engagement

Attempts were made to involve community members and organizations claiming to represent the community. On August 28, 2019, the project staff met with Ruhan Nagra of the University Network for Human Rights and one of the authors of the “Waiting to Die” document. On 11/1/2019, Drs. Trapido and Williams met with Dr. Rebekah Gee, the Secretary of the Health Department; Matthew Block of the Governor’s Office; and several lawyers claiming to represent the citizens of St. John. On November 4, 2019, Dr. Williams, Dr. Trapido, and several project staff along with Dr. Gee and a representative of the Governor’s Office held a town hall meeting in Reserve, LA to discuss the aims of the project

(https://www.youtube.com/watch?v=zCZvHc8MeF4&feature=youtu.be). Several phone calls were held with representatives of the Concerned Citizens of St. John and on January 20, 2020 Dr. Williams and Dr. Katner met with them in Reserve. By March, all face-to-face contact stopped due to the need to avoid gatherings due to the Covid-19 pandemic. However, throughout the course of the project, a number of calls were held with Ms. Nagra, Dr. Terrell of the Tulane Environmental Law Clinic, and representatives of Louisiana Environmental Action Network.

Results

Table 1 summarizes characteristics of surveyed households within the 2.5 km radius around the Denka Facility. We expected to approach all 1,821 households through door-to-door surveying, however due to the COVID-19 pandemic, our field workers were able to approach 236 households in person. Once door-to-door surveying was suspended, a multipronged approach was carried out: 1,710 households were mailed flyers, 375 P.O. boxes were sent flyers, and 1146 households were approached via telephone interviewing. There were 179 completed surveys where 83 households reported at least one cancer case compared to 96 households where no cancer was reported. Of the 179 completed surveys, 107 households were in Reserve, 23 households were in Edgard, and 49 households were in Laplace. There were 114 households that declined to participate in the survey of which 76 households did not indicate a reason for declining.

Table 1: Overall characteristics of surveyed households within the 2.5 km radius around the Denka Facility (N=1,821 households)	**n**
Recruitment strategies [a]	
Number of households approached via door to Door surveying	236
Number of households mailed flyers	1710
Number of PO Boxes mailed flyers	375
Number of households approached via phone surveying	1146
Completed surveys	179
Households that reported at least one cancer case	83
Households that have no cancers reported	96
Location completed surveys within 2.5 km survey area	179
Households located in Reserve	107
Households located in Edgard	23
Households located in Laplace	49
Number of households that decline to participate in survey	114
Declined without a reason	76
Family members have cancer, but the plant provides jobs and income into the community	1

Doesn't feel like anything can be done	1
Doesn't live in the parish anymore	18
Doesn't have time to do survey even after asked for better time to call	7
Former employees of Denka/DuPont	3
Have completed similar surveys in the past and doesn't want to participate in the current one	2
No cancers in household	4
Not interested in the current issues	1
No one over 21 available	1
Thought project staff were scammers even after explanation and contact information was given	1

[a] **Households were approached using multiple recruitment strategies.**

There were 141 individual cases reported by residents in the survey that the residents believed to be cancer. Table 2 represents all the resident-reported cases that were reviewed for the time period from 2009 through 2018. **Of the 50 cancers verified within the 2009-2018 time period, all cases were already documented in the LTR database; no reportable cancers were identified that were not a part of LTR data.** Additional information on resident-reported cancer cases can be found in the Appendix Section C – Figure 2.

Table 2: Cases for the time period 2009 – 2018 with sufficient information for review

Cases Community Reported	Verified as reportable cancer and in LTR database	Verified as reportable cancer and not in LTR database	Non-reportable by national standards	Medical records reviewed, no cancer diagnosis
85	50	0	16	19

Note: Appendix contains detailed figure explaining all resident-reported cancer cases **including those outside the 2009-2018 time period**.

Health conditions (other than cancer) were documented for all members of the households for both non-cancer and cancer households. Among health conditions reported by residents, the most prevalent conditions include 43 individuals have reported having allergies (mainly seasonal and sinus), 58 individuals reported with hypertension (high blood pressure), 42 individuals have been diagnosed with diabetes, and 21 individuals reported non-specific heart issues.

Table 3: Health Conditions reported other than cancer (≥15 resident responses)	**n**
Allergies	43
Asthma	19
Non-specific breathing and lung issues reported	19

Diabetes/low blood sugar	42
Heart issues	21
Hypertension	58
Migraines/headaches	15
No health conditions reported	131

Note: Table 3 does not include conditions caused by accidents (i.e. gunshot wound). Appendix contains additional health conditions reported by residents.

In addition to health conditions, the residents voiced their concerns about living in the survey area around the Denka Facility. Table 4 summarizes the main concerns voiced by residents during their interviews. The comments were documented in survey by LSUHSC field workers. Many residents indicated environmental concerns including 1) there is a chemical odor in the neighborhood, 2) there is residue (described as dust and/or film) found on cars and their properties, and 3) concerns about waste disposal from the plant. Health concerns include overall concern about getting cancer, as many family and neighbors have died from cancer and developed other health conditions including respiratory diseases. Another major concern indicated by the residents in their survey responses was the presence of the school near the Denka facility/plant.

Table 4: Community Concerns	**n**
Worried about getting cancer or know family and/or neighbors who had cancer	19
Indicated there is an odor area, poor air quality	35
Indicated there is residue/film/dust found on car and on property	36
Indicated they are worried about the children being around the plant	26
Indicated better communication and correspondence for the community about the chemical and risks	4
Indicated health concerns other than cancer	30
Concerned of another plant explosion	4
Indicated they did not any concerns	20

Note: Appendix contains comments under each category.

Discussion

1. **No reportable cancers were identified through community reporting that were not already contained in the LTR data. This is consistent with national awards to the LTR for data completeness.**
2. Not all cancers are reportable by national standards, for example, basal and squamous cell carcinomas of the skin. These particular cancers are extremely

common, very slow growing, and rarely if ever lead to death. It is understandable that communities would not have knowledge of national cancer reporting standards and would be concerned that these cancers are not in the LTR data. However, no cancer registry in the United States collects data on these cancers and it would be virtually impossible to draw any conclusions from collecting data on cancers that are considered non-reportable, as there are no data to which to compare. In addition, the inclusion of non-reportable information will artificially inflate the rates as compared to data adhering to national standards. Therefore, it is important to recognize self-reported cancer data have limitations that make it unusable for valid determinations of risk or rates**.**

3. It is usually very difficult to link cancer incidence directly to a specific exposure. As noted by Goodman, et al, attempts to make these links are confounded by issues such as long latency for cancer development (length of time between the exposure and the diagnosis of cancer), low statistical power of most analyses due to small numbers of cases, uncertain definitions of cluster boundaries and the population of interest, and in- and out-migration in the community[7]. It would be necessary to conduct long-term epidemiological studies to look at individual level-based exposure in persons with and without cancer to see if there is an association between the exposure and disease. **This is beyond the scope of the LTR data and such claims of association or lack thereof should not be made based solely upon LTR data.**
4. While this project was limited to the area around the Denka plant, the same methodologies are used throughout the state, supporting the fact that LTR data are accurate and complete statewide.
5. This report in **no way implies that there are no health effects** from long-term exposure to chloroprene. While it is difficult without any specific study to determine if there is a connection between chloroprene exposure in St. John and cancer, it is also not possible without these studies to determine that there is no connection. In 2010, the Environmental Protection Agency classified chloroprene as a likely carcinogen after identification as such by the International Agency for Research on Cancer[8]. In addition, this project does not address other health effects that could be related to chloroprene exposure.

Limitations

One limitation was this project relied on self-reported cancer diagnoses. Participants reported six cases for whom not enough information was available to track down medical records. Medical record matching requires unique identifying information such as date of birth or social security number, as well the name of the healthcare facility where the patient received care. For these six cases, simply not enough information could be provided by the interviewee. Additional contacts were made to attempt to receive additional information, but none was provided. In addition, with self-report,

there is always the possibility that there were additional cases that residents did not remember, or they were unaware of a cancer diagnosis.

Another limitation was determining which individuals represented community concerns or if they were representing their own concerns. Multiple people and organizations claimed to be representing the community. Some of these people and organizations clearly wanted to insert their influence into this project. We attempted to listen to everyone and to respond to concerns when appropriate. However, it was often difficult to determine if outsiders truly represented community concerns or if they were more likely to be representing their own concerns, or in the case of attorneys, their own interest in their legal cases. We did our best to balance project rigor with responding to legitimate community concerns.

Recommendations

1. This project does not identify any reportable cancer cases missed by LTR. We recommend the community focus on respiratory diseases based on self-reported health conditions in the survey responses.
2. If there is any resident who is questioning if their cancer diagnosis is included in the LTR and want to report their cancer diagnosis, they can report through the LTR website (https://sph.lsuhsc.edu/louisiana-tumor-registry/) and LTR staff will be able to verify if it is recorded in the database.

Conclusion

The LTR is an exceptional resource for learning about types of cancer, their frequency, the rates at which they occur, the distribution of cases, information on cancer stage and pathology, cancer treatment, and cancer survival. It is nationally and internationally recognized for its completeness, accuracy, and timeliness. However, the LTR does not contain information on the causes of cancer. The registry does not collect data on environmental conditions to which persons with cancer may have been exposed. Therefore, **the CRISP review and confirmation of cancers in St John parish can neither confirm nor refute any links between exposures to chemicals and cancer occurrence.**

Appendix

A. List of Reportable Cancer Diagnoses for Tumor Registries.[6]

The following are reportable based on national standards (NCI and CDC cancer registry guidelines):

- The LTR requires that all in situ and invasive neoplasms (cancers with behavior codes 2 or 3 in the ICD-O-3 manual) be reported. Carcinoid, NOS of the appendix is reportable, effective January 1, 2015, forward. Please note: the ICD-O-3 behavior code has changed from /1 to /3.
- 2016 ICD-O-3 Reportability
    - All Squamous Intraepithelial Neoplasias, grade III (SIN III) are reportable to the Louisiana Tumor Registry, including (but not limited to):
    - Anal Intraepithelial Neoplasia (AIN III–C21.0-C21.1)
    - Exception: AIN III (8077) arising in perianal skin (C445) is non-reportable
    - Cervical intraepithelial neoplasia (CIN III–C53.0-C53.9, effective January 1. 2009 forward). Please see CIN III Reporting Details
    - Conjunctival intraepithelial neoplasia/lesion (CIN III-C69.0)
    - Laryngeal Intraepithelial neoplasia (LIN III—C32.0-C32.9)
    - Lobular neoplasia, grade III (LN III), effective January 1, 2016, forward
    - Lobular intraepithelial neoplasia, grade III (LIN III), effective January 1, 2016, forward
    - Penile intraepithelial neoplasia, grade III (PeIN III—C600-C609), effective January 1, 2016, forward
    - Vaginal intraepithelial neoplasia (VAIN III—C52.9)
    - Vulvar intraepithelial neoplasia (VIN III—C51.0-C51.9)
    - Carcinoma in situ (CIS) of the cervix –effective January 1, 2009, forward, please see CIN III Reporting Details
    - All tumors of the brain and central nervous system (site codes C70.0-C72.9 and C75.1-C75.3 in the ICD-O-3 codebook) are to be reported, regardless of behavior code. Juvenile astrocytomas should be reported as M9421/3. (Benign brain and CNS tumors are reportable effective January 1, 2004.)
    - Positive urine cytology: Effective 2013, these should be reported if they document the presence of "positive malignant cells" or "(malignant) cells interpreted as carcinoma" and should be coded to C68.9 Urinary System NOS in the absence of any other information on the site of origin.
- Two exceptions to the instructions about reporting positive urine cytology:
    - If the positive urine cytology is later followed by a urinary site's negative tissue biopsy, DO NOT REPORT, as the pathology proved the cytology to be incorrect. The pathologic diagnosis is the "gold standard." When cytology and pathology disagree, always use the pathology. (SEER SINQ 20100106 & 20120079)

- Urine cytology utilizing ambiguous terminology is not reportable. For example, do not report urine cytology that is "suspicious for malignant cells."

B. List of Non-Reportable Cancer Diagnoses for Tumor Registries.[6]

The following are not reportable based on national standards (NCI and CDC cancer registry guidelines):

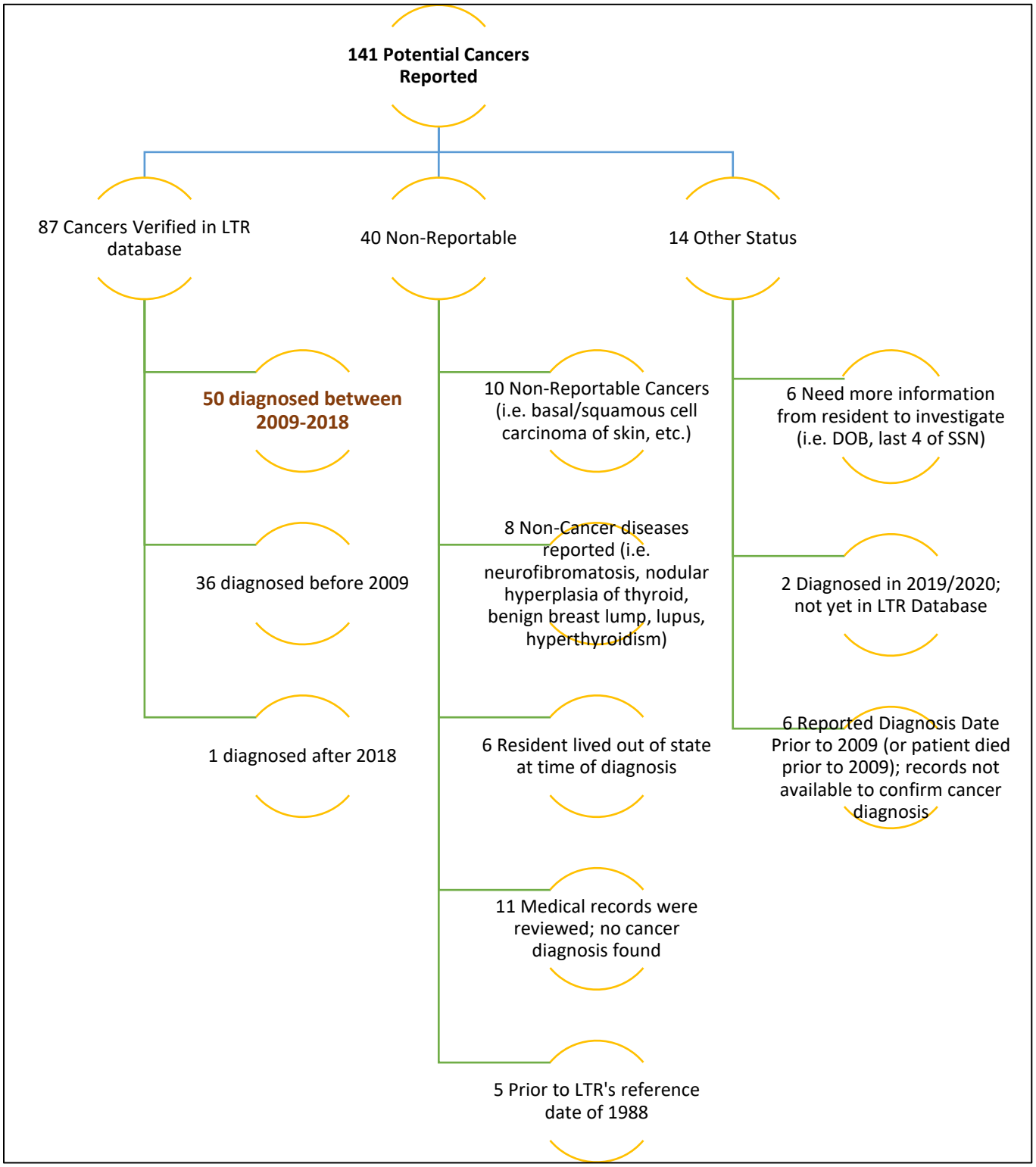
- Prostatic intraepithelial neoplasia, grade III (PIN III—after 1/1/2001)
- Squamous intraepithelial neoplasia of the cervix (CIN III—effective 1996-2008 only)
- Skin cancers (C44. range only) with histologies 8000-8005, 8010-8046, 8050-8084, and 8090-8110. These include, but are not limited to, basal cell and squamous cell carcinomas of the skin.

Note 1: All skin cancers (C44. range) with histologies other than those listed above must be reported.
Note 2: Skin cancers, regardless of histology, must be reported if they are not in the C44. range. This includes the following:

- The skin of the labia majoria, C51.0
- The skin of the penis C60.9
- The skin of the scrotum C63.2
- The skin of the vulva C51.9
- Certain Hematopoietic Diseases–several Hematopoietic diseases are similar to reportable Hematopoietic neoplasms.

C. Additional Tables and Figure

Figure 2: Summary of all resident-reported cases.



There were 87 reportable cancers verified in LTR database where 50 of these cancer cases were diagnosed between 2009-2018, 36 cancer cases were diagnosed before 2009, and 1 cancer case was diagnosed after 2018. Among the 141 resident-reported cancer cases, 40 cases were non-reportable by NCI and CDC case reporting requirements: 10 non-Reportable Cancers (i.e. basal/squamous cell carcinoma of skin, etc.), 8 Non-Cancer diseases reported (i.e. neurofibromatosis, nodular hyperplasia of thyroid, benign breast lump, lupus, hyperthyroidism), 6 cases were from residents who were not Louisiana residents at time of diagnosis, 11 cases - medical records were reviewed and there was no cancer diagnosis found, and 5 cases were reported to be diagnosed prior to the LTR's reference date of 1988. There were 6 cases that needed more information from residents to research the cases. Residents were contacted multiple times but were not able to supply the necessary information. Two cases were diagnosed in 2019/2020, which are not yet in the LTR database. These cases have been identified by the healthcare facilities but have not yet been abstracted or submitted to the LTR. For state tumor registries, there is 2-year lag in between the end of a diagnosis year to publication of cancer statistics. Finally, there were 6 cases where the diagnosis dates were prior to 2009 (or resident died prior to 2009) and medical records were not available for review and verification of cancer.

Table 5: Characteristics of reportable cancers within 2009-2018 (N=50 individual cancers)	**n**
Types of reportable cancer [a]	
Lung	10
Breast	8
Prostate	7
Pancreas	4
Kidney	3
Head & Neck	3
Esophagus	2
Lymphoma	2
Ovary	1
Bladder	1
Brain	1
Penis	1
Testicle	1
Stomach	1
Colon	1
Liver	1
Corpus Uterus	1
Multiple Myeloma	1
Leukemia	1
Gender[b]	
Male	28
Female	20
Race[b]	
Black/ African American Non-Hispanic	30
White Non-Hispanic	15
Other	1
Unknown/Not Reported	2
Vital Status[b]	
Alive	26
Deceased	22
Smoking status[b]	
Current/Active smoker	8
Former smoker (quit)	14
Never smoker	26
Report other health conditions (non-cancer) [b]	
Yes	25

No	23
Worked at an industrial facility or plant? [b]	
Yes	23
No	25

[a] Cancer Reporting in St. John Parish verified cancers, 2009-2018, by cancer type. For cancer cases, residents were able to report multiple cancer cases for each individual.
[b] The total reflects individuals and not cancer cases.

Table 6: Health Conditions reported other than cancer	**n**
No health conditions reported	131
Acid reflex	2
ADHD/ADD	3
Allergies	44
Aneurism	3
Anxiety/depression/mental health	7
Arthritis	6
Asthma	19
Back problems	12
Benign brain tumor	2
Benign kidney "spot"	1
Benign spine tumor	1
Non-specific breathing and lung issues reported	19
Cerebral palsy	1
COPD	3
Degeneration of the retina	0
Dementia	3
Diabetes/low blood sugar	42
Disabled	3
eczema/rashes/constant skin irritation	3
Emphysema	3
Glaucoma	1
Hearing loss	2
Heart issues	21
High cholesterol,	9
Hospital due to unknown reaction after cutting grass. Became paralyzed.	1
Hypertension	58
Hypoglycemia	1
Kidney disease	7
Large cysts in ovaries	1
Learning disability	1
Liver issues	2
Migraines/headaches	15
Miscarriage	1

Nerve pain	4
Nosebleeds	2
Orthopedic problems/bone issues	3
Polyps in colon	2
Poor Vision/ No vision	1
Premature birth	2
Prostate issues	3
Psoriatic spasms	1
Rare blood disorder	1
Sarcoidosis respiratory disease	2
Scoliosis	3
Seizures	1
Sickle cell anemia	1
Sleep apnea	1
Stomach issues	3
Stroke	3
Thyroid issues	9

Note: Table does not include conditions caused by accidents (i.e. gunshot wound).

Table 7: Community concerns reported by survey respondents.	**n**
Cancer concerns	19
Worried about getting cancer	3
Mentioned family or/and neighbors have/have died of cancer	16
"Lot of neighbors, diagnosed with cancer. I know of 2 neighbors who died to unknown cancer." "I lost one uncle to lung cancer 2 years ago. He lived 1 mile away from me." "Lost mom to pancreatic cancer more than 15 years ago."	
Indicated there is an odor area, poor air quality	35
"Always odors in the air, smells like a chemical odor."	
"Bad smells at night and especially during a rainstorm. Odds smell when it rains badly, a chemical smell"	
"didn't realize plant odors blew into the air, chemicals in grass caused cows to die"	
“When Dupont owned it, the emissions would make it foggy in the air and it concerned them at the time; not hard to breathe, but at night time was the worst time with the air; environment is better after Denka took over; he hasn't noticed any bad air quality in a while, but there is still a lingering chemical smell.”	
Indicated there is residue/film/dust found on car and on property	36

"Yellow dust or pollen collects on cars even when not seasonal for pollen collection, vehicles are always dusty and have to pressure wash the ground in front of the property"	
"water quality is bad and each month they get notice that water quality is below standards; does not drink the water, only drinks bottled or filtered or Kentwood;"	
"Worried about all of the waste that comes from plants that gets injected into the grounds and wonders if they negatively affect the community."	
"Very poor air quality and smells chemicals all the time and more worried about the ones that you can't smell; dust on the cars, fine foggy dust, always has to put on windshield wipers to get material off in the morning; film develops on screen on back porch, very fine material since the screens are fine"	
"landscape (trees) is dying around the neighborhood (70% have died in the last two years)"	
"yellow dusty film on the cars in the mornings sometimes"	
"black soot/ashes would cover the vehicles in the morning"	
Indicated they are worried about the children being around the Denka facility/plant.	26
"School children by the plant, her grandchild became sick, had severe nosebleeds and became sick then after he left the school he became better"	
“grandchild left to 5th ward school and always sick (nosebleeds, asthma, anxiety, and headaches - he was couple of years) and left the school he no longer had the issues”	
“Worried since niece went to school near Denka and now at a high school 15 minutes from Denka and is concerned about the chemical smell and bad air quality. Niece has allergies and uses eye drops.”	
Indicated better communication and correspondence for the community about the chemical and risks.	4
Indicated health concerns other than cancer	30
"kids have skin allergies and respiratory issues"	
"lots of respiratory illnesses in the area - history of lung transplants of family members living down the street"	
"The quality of life is down due to plant. Always smell gas smell, dust on house and vehicle. Bothers them greatly. Interviewee has bad sinus issues. Great grandchildren in the family have asthma."	
"The emissions are bothersome. Wife gets upper respiratory infections frequently. Daughter complains about upper respiratory infections and skin irritations as well."	

"people have rashes that they don't know where they come from; doctors are not finding the source of medical problems, just patching things up and sending people away; not solving anything; "	
"so many people in the neighborhood has breathing problems, if she was younger - she would have moved out of the neighborhood"	
"Children are losing parents at young age in neighborhood. Big loss in the children's live and grandparents having a difficult time raising the children while dealing with health problems. The children need counseling and their life is turned upside down. I've seen children staring down at caskets and its heartbreaking."	
Concerned of another facility/plant explosion.	4
"concerned about another explosion, We suffered damage to the house and never got any compensation or inspection;"	
Residents indicated they did not have any concerns	20

Note: Comments were transcribed by field workers.

D. Cancer Reporting In St. John Parish (CRISP) Survey Instrument (Paper version – Adapted from REDcap Electronic version)

Section 1: Resident Tracking Form	
Record ID	
Interviewer#1: *Enter your name*	
Interviewer #2: *Enter your partner's name*	
Date and Time of Interview MM/DD/YYYY HH:MM	
Address	
Any notes about the residence: *Please provide any comments or concerns about this residence (e.g. they have a dog, etc.)*	
Was anyone home?	☐ Yes ☐ No
Were they interested in participating in the survey? [Verify the interviewee is at least 21 years old.]	☐ Yes ☐ No
Are you able to complete the survey with the resident now?	☐ Yes ☐ No
Please schedule an alternate time to complete the survey.	
Last Name	
First Name	
Date of alternate interview. MM/DD/YYYY	
Time of alternate interview. HH:MM	
Email joesmith@example.com	
Phone Number 504-xxx-xxxx	
Please indicate why they chose not to participate in the survey	
Did you leave a flier and business card?	☐ Yes ☐ No
Please indicate why information was not left at the address.	

Section 2: Start of Interview	
Section Header: *Please fill out the following information about the Interviewee [He/She will be assigned as Resident 1].*	
As stated before, we are part of a team working in response to community concerns about cancer in St. John parish.	
We need to identify all residents of Louisiana who had cancer diagnosed during the past ten years and live in specific areas in St. John parish. We are working with Community Leaders, the Governor's Office and the Louisiana Department of Health. We are collecting information on cancer among family members living at this and all other addresses nearby, to make sure that all individuals who had cancer have been reported to the state cancer database. Getting this information from you will provide valuable information- and it should take no more than 10 minutes of your time. All information you provide will only be shared with the Louisiana Tumor Registry- so they can check and validate their database. Once this is done, we shall report our results to St. John parish community leaders and residents, and to the Department of Health.	
Last Name *Enter family surname*	
First Name *Enter first name*	
Middle Name *Enter middle name.*	
Do you go by any other names?	☐ Yes ☐ No
Maiden Name	
Other alias for first name?	
Other alias for last name?	
Please verify address. *Enter house number and street information of the residence.*	
Apt # *Enter city of residence.*	
Zip code *Enter zip code of residence.*	
Start Year *Enter year when interviewee started living at the current residence.*	
Date of birth	__ /__ /_____
Was there anyone in the household who was diagnosed with cancer? *Select "Yes" if any member of the household had been diagnosed with cancer.*	☐ Yes ☐ No

Form will proceed to should proceed to Section 3 to answer questions of each member once Section 2 is completed. *Select "No" if no member of the household was diagnosed with cancer.* *Form will proceed to should proceed to Section 4 to document prior residents once Section 2 is completed.*	
Comments	
Section Header: *Please list current and prior members that resided at this address.*	
Reminder: Interviewee will be assigned as Resident 1 of the household.	

Section 2: Start of Interview (additional members) Note: (print additional copies of this form for to record prior residents in the last ten years.)	
Add another member of the household [Resident # ____]?	☐ Yes ☐ No
Last Name *Enter family surname*	
First Name *Enter first name*	
Middle Name *Enter middle name*	
Do you go by any other names?	☐ Yes ☐ No
Maiden Name	
Other alias for first name?	
Other alias for last name?	
Date of birth	__ /__ /_____
Start Year *Enter year when interviewee started living at the current residence.*	
Add another member of the household [Resident # ____]?	☐ Yes ☐ No
Last Name *Enter family surname*	
First Name *Enter first name*	
Middle Name *Enter middle name.*	
Do you go by any other names?	☐ Yes ☐ No
Maiden Name	
Other alias for first name?	
Other alias for last name?	
Date of birth	__ /__ /_____
Start Year *Enter year when interviewee started living at the current residence.*	

Section 3: Questions about members of the household Note: (print additional copies of this form to record additional household members in the last ten years.)	
Section Header: *Please answer the following questions about each member of the household:* *Last name:* *First name:*	
Please verify date of birth.	__ /__ /_____
Gender	☐ Female ☐ Male
Race	☐ American Indian/Alaska Native ☐ Asian ☐ Native Hawaiian or Other Pacific Islander ☐ Black or African American ☐ White ☐ More Than One Race ☐ Unknown / Not Reported ☐ Other
Other (please specify):	
Ethnicity	☐ Hispanic or Latino ☐ NOT Hispanic or Latino ☐ Unknown / Not Reported
Social Security Number (last 4 digits) *Please provide at least last four digits. If interviewee does not want to give SSN, enter "Not given".*	☐ Known ☐ Unknown ☐ Doesn't want to give
Social Security Number (last 4 digits)	XXX-XX-_____
Have you been diagnosed with cancer?	☐ Yes ☐ No

Type of cancer	☐ Bladder cancer ☐ Brain cancer ☐ Breast cancer ☐ Colon cancer ☐ Esophageal cancer ☐ Kidney cancer ☐ Leukemia ☐ Liver cancer ☐ Lung cancer ☐ Lymphoma ☐ Melanoma ☐ Oral cancer ☐ Ovarian cancer ☐ Pancreatic cancer ☐ Prostate cancer ☐ Sarcoma ☐ Skin cancer ☐ Spleen cancer ☐ Thyroid cancer ☐ Cervical cancer ☐ Endometrial cancer ☐ Other (specify):
Other cancer or area (specify):	
Diagnosis date *Enter when individual was diagnosed with cancer, if interviewee is not sure, please indicate in text box that date is estimated*	☐ Date is known ☐ Date is estimated ☐ Date is unknown
Diagnosis date *Enter when individual was diagnosed with cancer.*	__ /__ /_____
Estimated diagnosis date	
Facility diagnosed or treated the cancer *Enter where individual was diagnosed with cancer, if interviewee is not sure, please indicate in text box that information is guessed*	
Name of the doctors who diagnosed and/or treated this cancer *Enter who diagnosed the individual with cancer, if interviewee is not sure, please indicate in text box that information is guessed*	

Were you a permanent resident of Louisiana at the time of diagnosis?	☐ Yes ☐ No
Where were you a permanent resident of?	
Vital Status	☐ Alive ☐ Died
Relationship To Interviewee	
Comments	

Section 4: Former Residents

Note: (print additional copies of this form to record prior residents in the last ten years.)

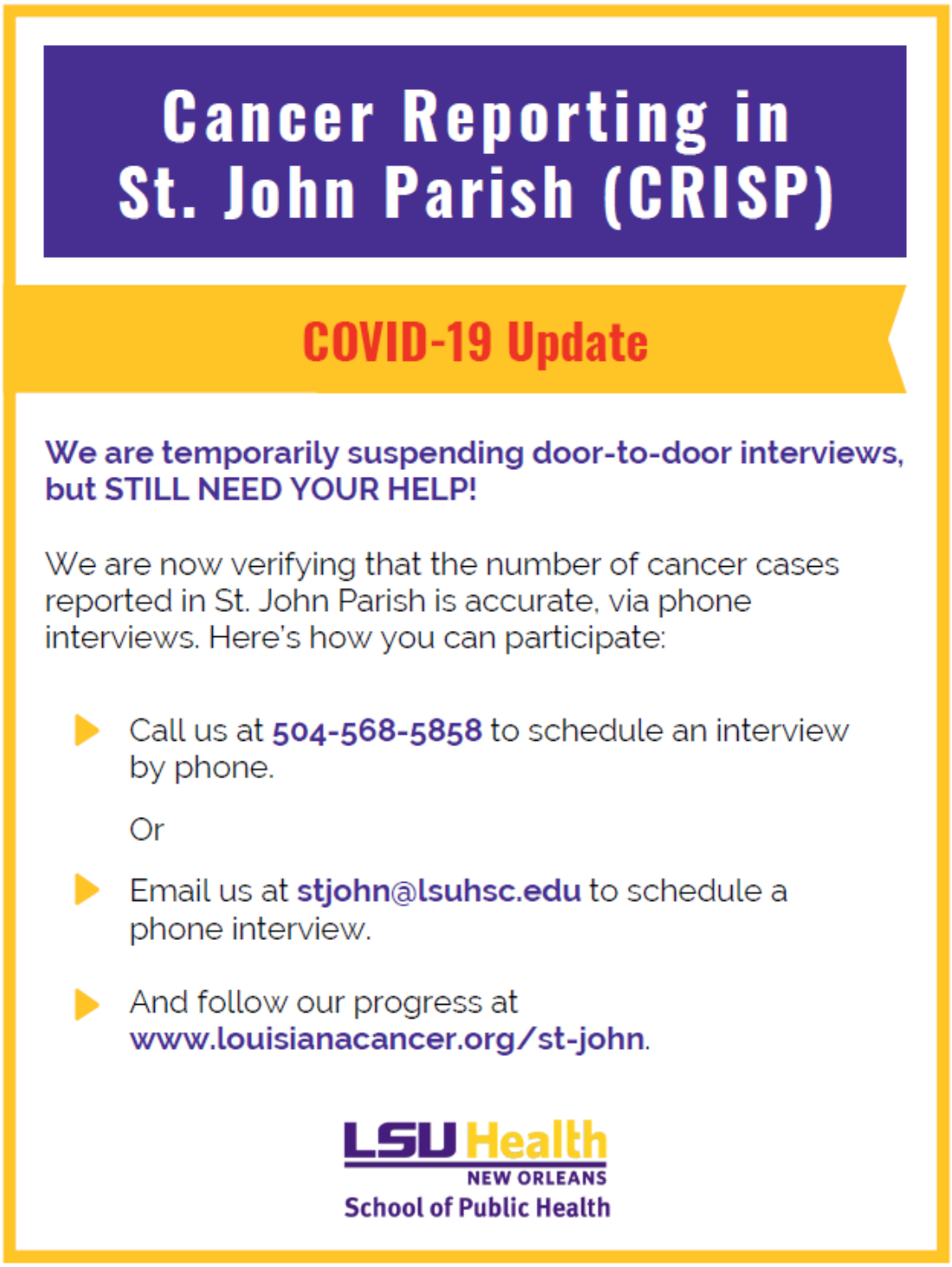
Section Header: *Part 3: Please list all the individuals who previously resided at this address during the last 10 years [Time period Jan 1, 2009 - Dec 31, 2018 i.e. 10-year data]*	
Do you remember any prior residents?	☐ Yes ☐ No
Last Name *Enter family surname including any former surnames, maiden names, etc.*	
First Name *Enter first name including given name, nick name, and any other alias they may go by.*	
Middle Name *Enter middle name.*	
Start Year *Enter start year at residence.*	
End Year *Enter end year at residence.*	
Comments	
Is there another former resident [Former Resident 2]?	☐ Yes ☐ No
Last Name *Enter family surname including any former surnames, maiden names, etc.*	
First Name *Enter first name including given name, nick name, and any other alias they may go by.*	
Middle Name *Enter middle name.*	
Start Year *Enter start year at residence.*	
End Year *Enter end year at residence.*	
Comments	

Section 5: Additional Questions
Note: (print additional copies of this form to record prior residents in the last ten years.)

Would you like to answer additional questions about your household?	☐ Yes ☐ No
Last name: *First name:*	
Has [resident name] ever smoked?	☐ Never ☐ Former (Quit) ☐ Current
Did [resident name] ever work on the property of an industrial facility or plant?	☐ Yes at Denka ☐ Yes at other facility ☐ No
Any additional health information you want to give about yourself:	
Last name: *First name:*	
Has [resident name] ever smoked?	☐ Never ☐ Former (Quit) ☐ Current
Did [resident name] ever work on the property of an industrial facility or plant?	☐ Yes at Denka ☐ Yes at other facility ☐ No
Any additional health information you want to give about:	

Section 6: Contact information and additional concerns	
Section Header: *We plan to send a letter informing you about the results found about your household.* Would you like to be informed of the results of your household?	☐ Yes ☐ No
Please confirm that you want the letter to be addressed to the following: *Please confirm contact information in Section 2*	☐ Yes ☐ No
If this is not correct, please indicate to whom and where you would like the letter to be sent.	
First Name Last name Address City Zip code	
We may need to contact you about further information about the responses you gave during this survey. What is your preferred phone number and email?	
Email Phone Number	
We are also collecting any additional concerns regarding the community and plant. Do you have any?	
Interviewer Comments	

E. Project Flyer (current COVID-19 version)



F. Cancer Incidence Rates in St. John the Baptist Parish

Cancer incidence rates for census tracts in St. John parish are provided. Because no cancers were found that had not been reported, these rates do not differ from rates previously reported by the Louisiana Tumor Registry. Rates have been calculated according to national standards.

Age adjusting is a mathematical way of comparing two different populations of people who may differ widely in age. For example, the average age in Alaska is 34 while the average age in Florida is 42. This makes sense because younger people are more likely to be adventurous and move to Alaska, while older people may retire in Florida for the warm climate. These differences are very important when comparing cancer data because the risk of having cancer goes up as we age. If we used the raw data, it would look like Florida has a very serious cancer problem when in fact, they just have a much higher percentage of older people living there and older people are more likely to get cancer. Age adjusting allows us to be able to compare people from Alaska to people from Florida as if they have the same average age.

Ages can vary widely in one geographic area. For example, rural areas tend to have much older populations than urban or suburban areas. Even within one city or town, older people might tend to live in areas that are mostly single-family homes because of their ability to save and buy a home versus younger people living in areas that are primarily rental properties.

Age adjusting is very important in comparing cancer rates. It would not make sense to compare geographic areas that have not been age adjusted to each other because of the potential for age differences. It is also not wise to try to compare adjusted areas to unadjusted areas. Age adjusting can be done for areas as small as a census tract because the U.S. Census collects age data. However, for the circles used for previous work in St. John, age adjusting would not be possible because reliable age data for those specific areas do not exist. **Therefore, the calculated cancer rates for the circles are unadjusted and should not be compared to other rates, adjusted or unadjusted. They are provided here for information only**.

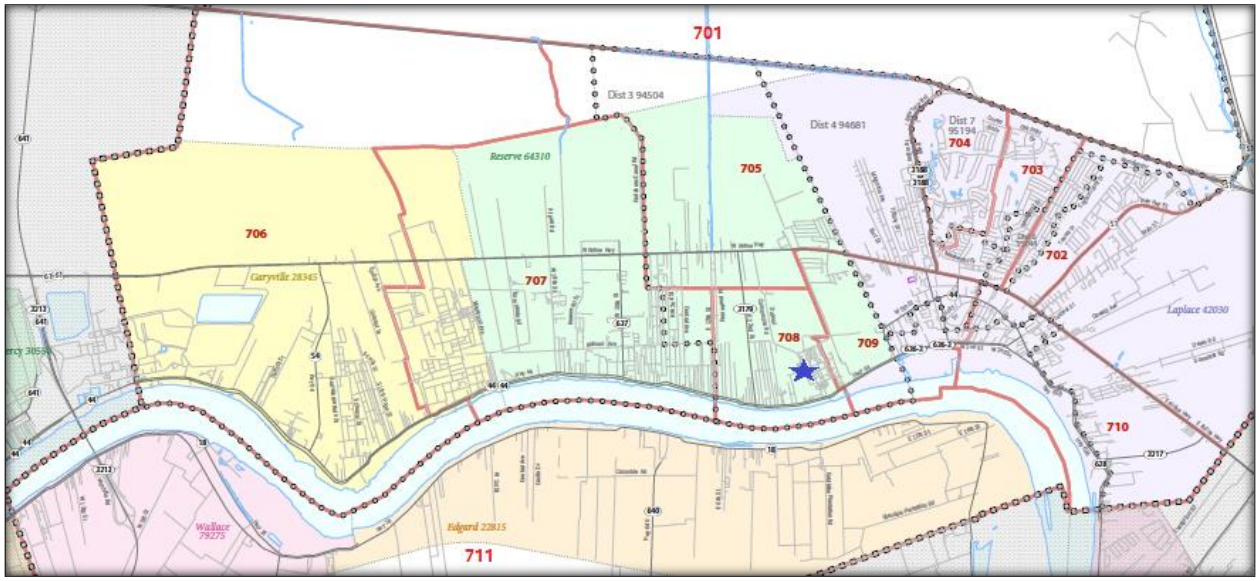


Figure 3: Census tract map for St. John Parish. Blue star indicates location of Denka Plant. Only a portion of tracts 701 and 711 are shown.

Table 8. Summary of age-adjusted incidence rates[#] for Louisiana and St. John Parish census tracts for 2008-2017

	All Sites	Prostate	Lung	Breast	CRC	NHL	Bladder
Louisiana	481.7	146.2	69.7	124.5	47.6	19.8	18.7
St. John the Baptist Census Tracts							
701	508.6	^	^	^	^	^	^
702	516.2	**234.4[a]**	63.4	125.4	54.6	**42.0[a]**	^
703	484.5	176.8	66.1	133.9	44.3	^	26.8
704	507.5	141.7	84.1	170.2	30.1	^	^
705	496.3	164.5	52.3	135.2	47.3	^	^
706	422.3	^	51.0	^	54.7	^	^
707	**365.4[b]**	**97.1[b]**	**44.1[b]**	80.5	39.9	^	^
708	564.8	^	77.6	^	59.8	^	^
709	**402.7[b]**	^	^	^	^	^	^
710	560.0	^	^	^	50.3	^	^
711	**408.7[b]**	^	55.1	^	^	^	^

Note:
[#]Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard.
[a]Red text indicates census tract has statistically significantly higher cancer incidence rates when compared to Louisiana state-wide rates.
[b]Blue text indicates census tract has statistically significantly lower cancer incidence rates when compared to Louisiana state-wide rates.
^Incidence rate did not meet publication criteria for census tract report. The publication criteria are as follows: census tracts must have a population of at least 20,000 for the ten-year period (2,000 per year) or at least 16 cancer cases were reported for the ten-year period. For additional information, please refer to

census tract report from LTR (https://sph.lsuhsc.edu/wp-content/uploads/2021/03/01_Cancer-Incidence-in-LA-by-Census-Tract-2008-2017.pdf).

Table 8 summarizes the age-adjusted cancer incidence rates for Louisiana and St. John Parish for 2008-2017 (refer to Figure 3 census tract map for specific locations). Based on this table, only census tract 702 (Area: Interstate 10-HWY 51-Airline HWY-canal/spillway) has statistically significantly higher cancer incidence rates for prostate at 234.4 (4.8 cases per year) and non-Hodgkin lymphoma at 42.0 (1.6 cases per year) when compared to Louisiana as a whole. Tract 707 has statistically significantly lower cancer incidence rates for all cancer sites combined at 365.4, for prostate cancer at 97.1, and lung cancer at 44.1. Tract 709 (Area: Denka-Airline HWY-Mississippi River-Larayo Park/Mahogany St/ Persimmon St) and 711 (Area: Wallace/Edgard) have statistically significantly lower overall cancer incidence rates at 402.7 and 408.7, respectively, compared to the Louisiana overall cancer incidence rate. All other census tracts for St. John have rates that are about the same as the overall Louisiana cancer incidence rate.

Table 9. Case count and calculated crude incidence rate[a] for St. John the Baptist Parish and Zones[b] around Denka (2009-2018)

Zone	# Cancer cases	# Cancer cases with census tract certainty[d]	Population[c]	Crude incidence rate based on all cases	Crude incidence rate based on cases w/ census tract certainty[d]
St John the Baptist Parish	2452	2427	45924	533.9	528.5
Zone 1 (within 1.5km radius)	149	149	2611	570.7	570.7
Zone 2 (within 2.5km radius)	476	476	10003	475.9	475.9

Note:
[a]Rates are per 100,000 and not age-adjusted as census tract block population by age is not available.
[b]Any census block that touches the circle (radius 1.5km or 2.5km) around Denka was considered within the zone.
[c]Population data source is the Census 2010 population on census tract block level.
[d]Census tract certainty is the basis of assignment of census tract for an individual record. The census tract data used for this table is based on complete and valid street address of residence. For additional information, please refer to census tract report from LTR (https://sph.lsuhsc.edu/wp-content/uploads/2021/03/01_Cancer-Incidence-in-LA-by-Census-Tract-2008-2017.pdf).

Table 9 summarizes calculations of the crude incidence rates for Zone 1 and Zone 2 areas (refer to Waiting to Die report) for 2009-2018 surrounding the Denka plant. The calculated crude incidence rates (non-adjusted) for Zone 1 and Zone 2 represent portions of census tracts 708, 709 and 711. These rates are not age-adjusted and should not be used to compare to the age-adjusted rates from the LTR.

References

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7. Goodman M, LaKind J, Fagnliano J, Lash T, Wiemels J, Winn D, Patel C, Eenwyk J, Kohler B, Schisterman E, Albert P, and Mattison D. *Int. J. Environ. Res. Public Health* 2014, *11*(2), 1479-1499.
8. Environmental Protection Agency. LaPlace, St. John the Baptist Parish, Louisiana | EPA in Louisiana. 2019. https://www.epa.gov/la/laplace-st-john-baptist-parish-louisiana. Accessed December 30, 2020.