AN EVALUATION OF THE GEORGIA COMPREHENSIVE CANCER REGISTRY

Improving an Established System

Introduction

Cancer is the second leading cause of death in Georgia, causing 1 in every 4 deaths per year\(^1\). Over 36,500 cases are diagnosed annually\(^2\), and Georgia’s lung and prostate cancer incidence and death rates are above national averages\(^3\). In 2005, cancer cost the state $4.6 billion\(^4\). This figure includes:

- $1.7 billion in direct medical costs
- $406 million in indirect morbidity costs
- $2.5 billion in indirect mortality costs

Many cancers are preventable and are associated with risk behaviors such as tobacco use, poor diet, and physical inactivity\(^1\). To combat this disease, in 1995, the Division of Public Health (DPH), Georgia Department of Human Resources, created the Georgia Comprehensive Cancer Registry (GCCR). The GCCR conducts statewide surveillance, collecting data on all cancer cases in Georgia. After ten years of operation, a total system evaluation was conducted. This involved assessing the following attributes, as defined by the Centers for Disease Control and Prevention (CDC) for evaluating surveillance systems\(^5\):

- Usefulness
- Simplicity
- Flexibility
- Data quality
- Sensitivity
- Acceptability
- Predictive value positive (PVP)
- Representativeness
- Timeliness
- Stability

Also of interest was whether the registry was achieving its goals and objectives, and whether a positive relationship existed with the reporting facilities. The evaluation identified system strengths as well as areas for improvement.

Key Findings

- The GCCR met its goals and objectives
- The GCCR scored highly on the evaluation attributes and standards
- The registry has a positive relationship with its reporting facilities and other stakeholders
- GCCR data inform Georgia cancer control programs and feed into national cancer databases
- GCCR provides data to researchers, educators, and policy makers

Conclusions

- GCCR met its stated goals and objectives:
  - GCCR meets national standards; it is Gold Certified by the North American Association of Central Cancer Registries
  - The registry performs well with respect to surveillance system attributes shown below:

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usefulness</td>
<td>High – met goals, no negative marks</td>
</tr>
<tr>
<td>Simplicity</td>
<td>High – as easy/easier to use than other systems</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Responds well to change</td>
</tr>
<tr>
<td>Data quality</td>
<td>Gold Certified for 5 years</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>≥ 95%</td>
</tr>
<tr>
<td>Acceptability</td>
<td>High</td>
</tr>
<tr>
<td>Predictive value positive (PVP)</td>
<td>100 %</td>
</tr>
<tr>
<td>Representativeness</td>
<td>97.6 %</td>
</tr>
<tr>
<td>Timeliness</td>
<td>Usually receive cases within 6 mo. of diagnosis</td>
</tr>
<tr>
<td>Stability</td>
<td>High reliability and availability</td>
</tr>
</tbody>
</table>

- Eighty-five percent of reporting hospitals surveyed rated their relationship with GCCR as positive. Very few negative comments were received from any of the stakeholder groups.
- Some opportunities for improvement exist; if GCCR acts on these opportunities, the system can continue to improve and serve as an example to other registries.
Methodology

Design
The evaluation was based on CDC guidelines for evaluating surveillance systems\(^5\) and the Joint Committee Program Evaluation Standards\(^6\).

Data Collection
Data were collected by a documentation review, stakeholder interviews, and an online survey. GCCR staff provided system documentation including the Policies and Procedures Manual, internal reports, and presentations. The GCCR Director provided contact information for stakeholders. Four different stakeholder groups were identified: internal registry staff, the funder (CDC), data users (researchers, health educators, policy makers), and reporting facilities. A few were selected for interview by the GCCR Director. Interviews were conducted in person or over the telephone.

All stakeholders were invited to participate in the anonymous online survey, based on the CDC guidelines and the Program Evaluation Standards. A different version of the survey was created for each stakeholder group. The surveys were reviewed by GCCR and peers with questionnaire expertise. The survey was administered using SurveyMonkey, a free survey tool\(^7\). The initial solicitation was made via phone and email, and participants were given a two-week timeframe (March 6 to March 20, 2006) to complete the survey. A reminder email was sent at the beginning of the second week.

Survey response rates:

<table>
<thead>
<tr>
<th>Group</th>
<th>Respondents</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal GCCR staff</td>
<td>6/8</td>
<td>75%</td>
</tr>
<tr>
<td>Funder (CDC)</td>
<td>1/1</td>
<td>100%</td>
</tr>
<tr>
<td>Data users</td>
<td>11/17</td>
<td>65%</td>
</tr>
<tr>
<td>Reporting hospitals</td>
<td>40/116</td>
<td>35%</td>
</tr>
</tbody>
</table>

Results

Data from Documentation

Summary
- Sophisticated, complex registry
- Very detailed policies and procedures
- Provides training to reporters
- Technologically advanced

Data Quality
- High data quality – Gold Certified by the North American Association of Central Cancer Registries (NAACCR) 1999-2003
- 15 audits in 2004; 27 in 2005
- Potential duplicates reviewed individually

Sensitivity
Definition: \(\frac{\text{# of cancer cases captured by GCCR}}{\text{Total # of cases, according to active surveillance and other sources}}\)

GCCR sensitivity indicated by completion rates:
\(\geq 95\%\) of GCCR cases are complete within 24 months of end of diagnosis year

Predictive Value Positive (PVP)
Definition: number of cases in system that are true cancer cases

GCCR PVP:
- 100\% of cases are true cases
- 97\% histologically confirmed
- 3\% clinically confirmed

Stability
- Reliability:
  - Consistently collects and provides data
  - Data completeness by national deadlines
- Availability:
  - Consistently operational when needed
  - Robust backup system

Each of Georgia’s cancer surveillance regions were represented by the hospital survey responses:

<table>
<thead>
<tr>
<th>Region</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>North</td>
<td>8</td>
</tr>
<tr>
<td>Metro</td>
<td>7</td>
</tr>
<tr>
<td>Central</td>
<td>7</td>
</tr>
<tr>
<td>Southeast</td>
<td>7</td>
</tr>
<tr>
<td>Southwest</td>
<td>5</td>
</tr>
</tbody>
</table>
**Representativeness**

Representativeness is a measure of how accurately the information in the system portrays the occurrence of cancer in the population, including distribution by person, place, and time. GCCR has excellent sensitivity, and therefore its representativeness is very good. One measure of sensitivity is the percentage of cases detected:

\[
\text{System detection rate} = \frac{\text{Total system cases} - \text{Cases detected by death certificate only}}{\text{Total system cases}} \times 100\%
\]

(2002 data)

**Data from Interviews**

**Summary**

- 168 facilities report to GCCR
- High data security
- National leader – Emory’s Georgia Center for Cancer Statistics (GCCS), a GCCR partner, assisted in creating the basis for AbstractPlus data abstraction software, which other states now use
- GCCR data directly drive GDPH cancer control and prevention programs
- Most time-consuming task for GCCS is processing of pending records, automation could improve timeliness of data completion

**Data from Online Survey**

**Usefulness**

Generally very high ratings
Negative marks: 0

*Internal staff:*
Could promote research more

**Simplicity / Ease of Use**

Strong reporting, dissemination methods

<table>
<thead>
<tr>
<th>Group</th>
<th>Excellent</th>
<th>Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal staff</td>
<td>83% (n=5)</td>
<td>17%  (n=1)</td>
</tr>
<tr>
<td>Data users</td>
<td>56% (n=5)</td>
<td>33%  (n=3)</td>
</tr>
<tr>
<td>Reporting facilities</td>
<td>24% (n=8)</td>
<td>49%  (n=16)</td>
</tr>
</tbody>
</table>

*Internal staff:*
- Improve funding, staffing, data submission discrepancies 33% (n=1)

*Data users:*
- Improve data collection rate 50% (n=1)
- Fewest high marks on integration with other systems 46% (n=5)

**Simplicity: Reporters' Desired Changes**

“Be able to track all cases submitted in one place, better productivity reporting, and easy access to all data requirements by diagnosis date”

“Better communication between GCCR and the hospital registry”

“Have list of all abstracts submitted rather than just the ones done with the last software update”

**Simplicity: Training Received by Reporting Hospitals**

<table>
<thead>
<tr>
<th>Training Level</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>GCCR annual training</td>
<td>20</td>
<td>61%</td>
</tr>
<tr>
<td>Informal training by supervisor or colleague</td>
<td>16</td>
<td>49%</td>
</tr>
<tr>
<td>National training by Director of Emory’s Georgia Center for Cancer Statistics</td>
<td>14</td>
<td>42%</td>
</tr>
<tr>
<td>Formal training by GCCR staff</td>
<td>13</td>
<td>39%</td>
</tr>
<tr>
<td>None received, will receive in future</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>None received, none planned</td>
<td>1</td>
<td>3%</td>
</tr>
</tbody>
</table>

* For numbers reported in this format, n is the number of respondents that selected this answer choice or provided this answer, and % is the percentage that n represents, of all respondents for that question.
**Flexibility**  
GCCR responds well to change

*Reporting facilities:*
- Policy & Procedures Manual update was:  
  - Excellent: 26% (n=8)  
  - Good: 55% (n=17)  
- Georgia EDITS * update was:  
  - Excellent: 52% (n=12)  
  - Good: 35% (n=8)  
- Somewhat quick response to change: 59% (n=19)

* EDITS is quality control software used by reporting facilities

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**Acceptability**

*Internal staff:*
- Facilities are very willing to report: 50% (n=3)  
- Facilities are willing to report: 50% (n=3)  
- Usual completeness rate for facilities: 80%-90%  
- Usual delay in reporting: 6-12 mo.

*Reporting facilities perceived that:*
- Their facility’s completeness rate was between 90%-100% for the 2004 diagnosis year: 79% (n=26)  
- Their completeness rate for 2004 was achieved within 6-12 mo. 60% (n=18)  
- Their facility submits data in a timely manner: 94% (n=32)

**Acceptability: Difficulty of Reporting**

Reporting facilities’ responses to the question, “How difficult is it for you or your facility to report cases?”

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**Barriers Cited by Reporting Facilities to Obtaining Complete Data**

<table>
<thead>
<tr>
<th>Barrier</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical record is missing information</td>
<td>23</td>
<td>79%</td>
</tr>
<tr>
<td>Medical staff do not understand requirements</td>
<td>9</td>
<td>31%</td>
</tr>
<tr>
<td>Medical staff not cooperative</td>
<td>7</td>
<td>24%</td>
</tr>
<tr>
<td>Difficulties getting data from other departments</td>
<td>5</td>
<td>17%</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>Missing pathology reports</td>
<td>2</td>
<td>7%</td>
</tr>
</tbody>
</table>
Acceptability: Quality of Relationships

*Reporting facilities:*

- Relationship with GCCR is
  - Not difficult: 85% (n=28)
  - Poor: 3% (n=1)
- Poor relationship with Regional Coordinator: 6% (n=2)
- GCCR “pushes” just enough for timely reporting: 85% (n=28)

Timeliness: Last Georgia EDITS Upgrade

Reporting facilities’ responses to the question, “With your most recent upgrade to include the Collaborative Stage fields, was the most recent Georgia EDITS software integrated into your software system in a timely manner?”

Timeliness

The survey also asked about perceptions (independent of documentation) of other aspects of timeliness.

*Internal staff felt that:*
- Cases are usually received within 6 months of diagnosis: 83% (n=5)
- 2003 data completeness 18-24 months after end of year: 83% (n=5)

*Data users felt that:*
- GCCR responds very or somewhat quickly to requests: 100% (n=9)

*Reporting facilities perceived that:*
- They achieved 2003 data completeness within 18-24 months (independent of actual time facility took): 90% (n=26)
Online Survey Summary
- Generally very positive remarks from all groups on all attributes
- Very few negative comments
- Untrained respondents who gave negative remarks commented on things that could have been addressed in training

Recommendations
Areas for improvement include:
- Improve reporting from physicians’ offices
- Automate processing of pending records
- Better identify risk groups, behaviors
- Expand, promote trainings
- Encourage more research outside of Metro Atlanta
- Advertise reports more and beyond normal channels

References

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For more information and resources about programs to address cancer in Georgia, please visit http://health.state.ga.us/programs/cancer/ or contact

Rana Bayakly, M.P.H.
Director,
Georgia Comprehensive Cancer Registry
2 Peachtree Street, NW, 14-283
Atlanta, GA 30303-3142
(404) 657-3103
arbayakly@dhr.state.ga.us

Kimberly S. Clay, Ph.D., M.P.H., M.S.W.
Manager, Comprehensive Cancer Control
Chronic Disease Prevention and Health Promotion Branch
2 Peachtree Street, NW, 16-274
Atlanta GA 30303-3142
(404) 657-6315
ksclay@dhr.state.ga.us

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