AN EVALUATION OF THE GEORGIA COMPREHENSIVE CANCER REGISTRY

Improving an Established System

DHR GEORGIA DEPARTMENT OF HUMAN RESOURCES

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 Goals and Objectives	Met
Collect data on cancer cases	✓
Calculate incidence and mortality rates	✓
Identify and track trends	✓
Provide data to cancer programs	✓
Identify high risk groups and risk behaviors	✓
Provide data to the public, educators, healthcare professionals, and researchers	✓
Promote cancer research	✓

- 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:

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

- 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:

Group	Respondents	Rate
Internal GCCR staff	6/8	75%
Funder (CDC)	1/1	100%
Data users	11/17	65%
Reporting hospitals	40/116	35%

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

Region	Respondents
North	8
Metro	7
Central	7
Southeast	7
Southwest	5

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:
≥ 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

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:

Total system cases	-	Cases detected by death certificate only	=	System detection rate	
↓		↓		↓	
100 %	-	2.4 %	=	97.6 %	(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

Data users:

Registry "completely met" objectives:

Tracking trends:	80% (n=8) *
Providing data:	80% (n=8)
Identifying risk groups:	56% (n=5)

Simplicity / Ease of Use

Strong reporting, dissemination methods
Group ratings:

Group	Excellent	Good
Internal staff	83 % (n=5)	17 % (n=1)
Data users	56 % (n=5)	33 % (n=3)
Reporting facilities	24 % (n=8)	49 % (n=16)

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)

Reporting facilities:

- As easy/easier than other systems to use: 94% (n=17)
- Low marks from those with less training
  - Hard to use: 6% (n=1)
  - Too many requirements: 11% (n=4)
- Fewest high marks given for time spent collecting data

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

Training Level	n	%
GCCR annual training	20	61%
Informal training by supervisor or colleague	16	49%
National training by Director of Emory's Georgia Center for Cancer Statistics	14	42%
Formal training by GCCR staff	13	39%
None received, will receive in future	1	3%
None received, none planned	1	3%

* 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:

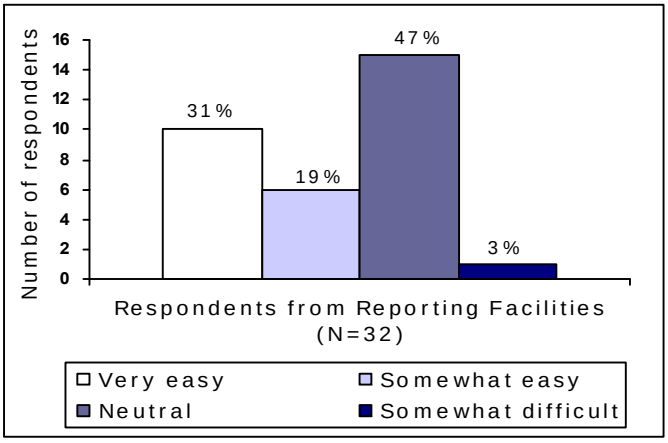
- Facilities are very willing to report: 50% (n=3)
- Facilities are willing to report: 50% (n=3)
- Usual completeness rate for facilities: 80%-90%
- Usual delay in reporting: 6-12 mo.

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?"



Barriers Cited by Reporting Facilities to Obtaining Complete Data

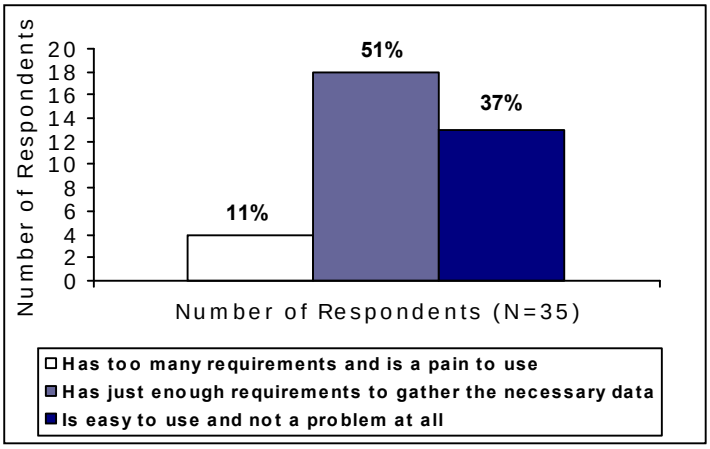
Barrier	n	%
Medical record is missing information	23	79%
Medical staff do not understand requirements	9	31%
Medical staff not cooperative	7	24%
Difficulties getting data from other departments	5	17%
Missing data	3	10%
Missing pathology reports	2	7%

Acceptability: Quality of Relationships

Reporting facilities:

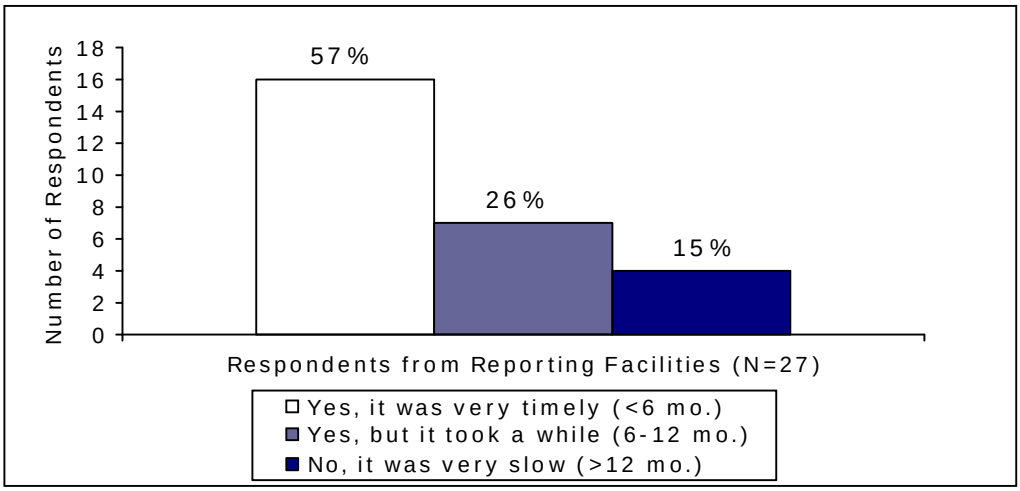
- Relationship with GCCR is
  - Not difficult: 85% (n=28)
  - Poor: 3% (n=1)
- Poor relationship with Regional Coordinator: 6% (n=2)
- GCCR "pushes" just enough for timely reporting: 85% (n=28)

Reporting facilities' completion of the statement, "I feel that the GCCR…"



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
- 2003 data completeness 18-24 months after end of year: 83% (n=5)
- GCCR responds quickly to requests (within 30 days): 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

1. Bayakly, A.R., McNamara, C., Singh, S., Steiner, C.B., Chowdhury, P.P., Martin, L.M., & Foster, G. (2005). Georgia Cancer Data Report, 2004. Atlanta, GA: Georgia Department of Human Resources, Division of Public Health, Chronic Disease, Injury, and Environmental Epidemiology Section, and the American Cancer Society, South Atlantic Division.
2. Centers for Disease Control and Prevention. (2005). Cancer. Retrieved February 13, 2006, from http://www.cdc.gov/node.do/id/0900f3ec80193c0d
3. Centers for Disease Control and Prevention. (2005). United States Cancer Statistics: 1999–2002 Incidence and Mortality Web-based Report. Retrieved February 21, 2006, from www.cdc.gov/cancer/npcr/uscs
4. Singh S., Bayakly A.R., McNamara C., Redding K., Thompson S.K., & Wall K. (2006). Georgia Cancer Data Report, 2005. Georgia Department of Human Resources, Division of Public Health, Chronic Disease, Injury, and Environmental Epidemiology Section, and the American Cancer Society, Southeast Division.
5. Centers for Disease Control and Prevention. (2001). Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. MMWR 50 (No. RR-13), 1-35.
6. Joint Committee on Standards for Educational Evaluation. (1994). The program evaluation standards: how to assess evaluations of educational programs. 2nd Edition. Thousand Oaks, California: SAGE Publications, Inc.
7. SurveyMonkey.com LLC. (2006). SurveyMonkey.com home page. Retrieved June 29, 2006, from www.surveymonkey.com

Acknowledgements

This project was a collaborative effort between the Georgia Department of Human Resources, Division of Public Health, Epidemiology Branch, Chronic Disease, Injury, and Environmental Epidemiology (CDIEE) Section, the Council of State and Territorial Epidemiologists (CSTE), and the Centers for Disease Control and Prevention (CDC). This evaluation was supported in part by an appointment to the Applied Epidemiology Fellowship Program administered by CSTE and funded by CDC Cooperative Agreement U60/CCU007277.

The author would like to thank the survey participants, the GCCR, and the following from the Division of Public Health:

- Rana Bayakly, M.P.H., Director, Georgia Comprehensive Cancer Registry
- Dafna Kanny, Ph.D., Deputy Section Chief, Chronic Disease, Injury, and Environmental Epidemiology Section
- John Horan, M.D., M.P.H., Chief, Chronic Disease, Injury, and Environmental Epidemiology Section

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

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Suggested citation: Clarkson, LS. *An Evaluation of the Georgia Comprehensive Cancer Registry: Improving an Established System.* Georgia Department of Human Resources, Division of Public Health, February 2007.
Publication Number: DPH07/004HW.