

MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION

SFN 2053 (2/85) 5M



ROLL NUMBER

DESCRIPTION

1117

2005 HOUSE HUMAN SERVICES

HB 1117

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1117

House Human Services Committee

Conference Committee

Hearing Date: 1/11/05

Tape Number	Side A	Side B	Meter #
2		x	830-4026

Committee Clerk Signature



Minutes:

Chairman Price opened hearing. Eleven members present, one absent.

Danielle Kenneweg, Director Division of Cancer Prevention and Control, State of North Dakota.

See Attached Testimony.

Rep. Porter: Is the data entered in to a data base?

D. Kenneweg: Yes, we have started the process.

Rep. Weisz: Do you have Federal funding?

D. Kenneweg: We receive \$398,000.00 in Federal funding. It is a 60/20 state funding match.

Rep. Weisz: If you have been doing this 1994, why are we presenting the new law.

D. Kenneweg: This is a Federal requirement for federal funding.

Rep. Nelson: Do the hospitals/physicians do it with out pay?

D. Kenneweg: Yes

Rep. Nelson: How cumbersome is this, knowing the importance. Is the paperwork user friendly?

D. Kenneweg: 150 points, staff can assist with the paper work.

Chairman Price: If a patient starts in a small clinic and is referred out, that patient can generate 4-5 reports.

D. Kenneweg: Yes.

Chairman Price: Does this cause confusion?

D. Kenneweg: Hopefully, none.

Chairman Price: Will this be covered under the Health review?

D. Kenneweg: It should be.

Rep. Porter: Under legislation, is it making this mandatory?

D. Kenneweg: This is already required.

Rep. Porter: Is this different regarding notification?

D. Kenneweg: It is already in force?

Rep. Porter: Is there a penalty?

D. Kenneweg: No, there is not.

Rep. Nelson: What information, data and what is done with it when collected?

D. Kenneweg: It is in the process, 6 years worth of data, this gives us the opportunity to look at trends.

Rep. Nelson: When will the report be done?

D. Kenneweg: In June.

Chairman Price: Electronic system included?

D. Kenneweg: It is in discussion to adapt a combined system - consolidate the electronic system.

Rep. Weisz: How many incidents of cancer do we know of now.

D. Kenneweg: Approximately 3,100 per year.

Judith Whitmeyer: Med Center/St.Alex/Cancer Center.

I am here as a cancer patient, and also to inform you that the doctors have very little time to spend on this, so it allows us to collect information that is used state wide.

Chairman Price: As a citizen, how do you find out about the registry?

J. Whitmeyer: One benefit is that I can find out if anyone has the same type of cancer, doctor's who are treating it, and information on the treatments.

Dave Peske, American Medical Assn.

Regarding the physicians, State Health Dept. requirements, concerning the federal grant, they have no problem with it.

Close hearing on HB 1117. (MR-3443)

Discussion:

Rep. Kaldor: How much is it costing to collect data ?

Chairman Price: As I understand it, \$150.00 each incident.

Rep. Kreidt: It seems to me you would need 5-6 years to collect data to make any reasonable determination.

Rep. Weisz: We know what we have to do, but it seems \$550,000 a biennium to do it, it is a lot

Rep. Porter: I can certainly understand Rep. Weisz's concerns of this bill, but we have to take into consideration, but even though this state agency hasn't provided certain information on

where patients have been treated successfully and what the national trends are regarding whether or not they could keep that patient in the local community or transfer to other facility to do the chemotherapy. There certainly is interaction between the national and the state data base, as the data base is to allow health care providers to find the best care for their patients and what is working and what isn't and where they need to be treated.

Rep. Weisz: I support we need to do the registry, but I have a problem with spending that amount of money to collect such specialized and limited information.

Rep. Devlin: Motion Do Pass, Rep. Porter: Second Vote: 11-0-1 Carrier: Rep. Porter
(MR -4026)

FISCAL NOTE
 Requested by Legislative Council
 12/22/2004

Bill/Resolution No.: HB 1117

1A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

1B. **County, city, and school district fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

House Bill 1117 provides statutory language specifically authorizing the Department of Health to maintain a cancer registry. The cancer registry was initiated approximately ten years ago when the Emergency Commission approved federal funding for this program. Spending authority for the program has been included in the department's biennial appropriations ever since and continues to be requested in the 2005-07 governor's recommended budget.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

Name: Arvy J. Smith
 Phone Number: 328-3070

Agency: Department of Health
 Date Prepared: 12/23/2004

Date: 1/11/04

Roll Call Vote #: /

2005 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1117

House

Human Services

Committee

Check here for Conference Committee

Legislative Council Amendment Number

Action Taken *Do Pass*

Motion Made By *Devlin*

Seconded By *Porter*

Representatives	Yes	No	Representatives	Yes	No
Chairman C.S. Price	<input checked="" type="checkbox"/>		Rep.L. Kaldor	<input checked="" type="checkbox"/>	
V Chrm.G. Kreidt	<input checked="" type="checkbox"/>		Rep.L. Potter	<input checked="" type="checkbox"/>	AB
Rep. V. Pietsch	<input checked="" type="checkbox"/>		Rep.S. Sandvig	<input checked="" type="checkbox"/>	
Rep.J.O. Nelson	<input checked="" type="checkbox"/>				
Rep.W.R. Devlin	<input checked="" type="checkbox"/>				
Rep.T. Porter	<input checked="" type="checkbox"/>				
Rep.G. Uglem	<input checked="" type="checkbox"/>				
Rep C. Damschen	<input checked="" type="checkbox"/>				
Rep.R. Weisz	<input checked="" type="checkbox"/>				

Total () 11 No 0

Absent /

Floor Assignment *Porter*

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
January 11, 2005 4:40 p.m.

Module No: HR-06-0315
Carrier: Porter
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HB 1117: Human Services Committee (Rep. Price, Chairman) recommends DO PASS
(11 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). HB 1117 was placed on the
Eleventh order on the calendar.

2005 SENATE HUMAN SERVICES

HB 1117

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1117

Senate Human Services Committee

Conference Committee

Hearing Date February 14, 2005

Tape Number	Side A	Side B	Meter #
1	x		1750-3460

Committee Clerk Signature



Minutes:

Chairman Lee opened the public hearing on HB 1117. All members were present.

This bill relates to authority of the state department of health to maintain a cancer registry.

Testimony in favor of HB 1117

Danielle Kenneweg, Director of the Division of Cancer Prevention and Control for the North Dakota Department of Health. See written testimony (Attachment 1)

Chairman Lee: Why is the brain tumor registry separate from the cancer registry?

Kenneweg: It's a separate research group established in cooperation with the other national organizations to look just at brain tumors/cancers.

Sen. Warner: Do you have information regarding geographic locations?

Kenneweg: There are 150 data elements we collect on incidents of cancer. We ask for a residential location. However, a barrier is when hospitals or clinics report post office boxes as

locations. But we are working with our data base system on a geoquoting system as well to begin to analyze those kind of situations as well. This would address those environmental issues.

When you have small numbers like we do in rural areas of North Dakota, it would not protect someone's privacy to report that there was one case of brain cancer in a small county because most people would know who that individual is. Due to federal and state law, we protect that information very carefully. When we are reporting, we suppress any cases that are less than five.

Sen. Brown: You applied for a grant in 1994, I assume you got it shortly thereafter, and you've been working at it, why do you need the change in the law?

Kenneweg: The federal law asks that you have state law authorizing the registry. When we received funding in 1994, we came to the emergency commission and requested authority to spend money and money to hire an SPE. We've been operating the registry under the general authority of the state health officer. We're now just trying to come into compliance with that federal requirement.

Sen. Dever: Have you found any certain types of cancer in North Dakota that's different from the rest of the country? What kind of steps are taken to deal with that?

Kenneweg: There are five leading cancers in North Dakota and they tend to be the same as the rest of the country. Those are bladder, prostate, breast, lung and colorectal. What do we do with that information? We are currently in the middle of a data study for the comprehensive cancer program to look at what the data tells us about cancer. This report is due in June. We're a very young registry, we started collecting data in 1997, others are 30-40 years old. We're just starting to be able to see trends.

Chairman Lee: Are there state universities that are doing any research about the kind of things that we've discussed here?

Kenneweg: We get requests from lots of researchers, many of which are from universities. But we don't know what kind of research they're doing.

Sen. Lyson: I've noticed that there's a high incidence of pancreatic cancer in Williston.

Kenneweg: We've been made aware of that concern. We have looked at the data and have been in response to individuals who questioned it.

Donna Bosch, testifying for Dr. Kevin, Oncologist from Minot. See written testimony (Attachment 2)

There was no further testimony for HB 1117

Chairman Lee closed the public hearing on HB 1117

Senator Warner moved DO PASS on HB 1117, seconded by Senator Brown

Vote: 5 yeas, 0 nays, 0 absent Carrier: Senator Brown

Date: 2-14-05
Roll Call Vote #: 1

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1117

Senate Human Services

Committee

Check here for Conference Committee

Legislative Council Amendment Number

Action Taken *Do Pass*

Motion Made By *Sen Warner* Seconded By *Sen. Brown*

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee - Chairman	✓		Sen. John Warner	✓	
Sen. Dick Dever - Vice Chairman	✓				
Sen. Richard Brown	✓				
Sen. Stanley Lyson	✓				

Total (Yes) *5* No *0*

Absent *0*

Floor Assignment *Sen. Brown*

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
February 14, 2005 1:05 p.m.

Module No: SR-28-2782
Carrier: Brown
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HB 1117: Human Services Committee (Sen. J. Lee, Chairman) recommends DO PASS
(5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1117 was placed on the
Fourteenth order on the calendar.

2005 TESTIMONY

HB 1117

Testimony

House Bill 1117

House Human Services Committee

Tuesday, January 11, 2005

North Dakota Department of Health

Good afternoon, Madam Chair and members of the House Human Services Committee. My name is Danielle Kenneweg, and I am director of the Division of Cancer Prevention and Control for the North Dakota Department of Health. I am here today to testify in support of House Bill 1117.

In 1992, the United States Congress passed legislation authorizing funding to establish cancer registries in states that did not have them. As a result of that legislation, North Dakota became eligible to apply for cancer registry funding from the U.S. Centers for Disease Control and Prevention (CDC). The North Dakota Department of Health applied for and received that funding in 1994. In order to qualify for funding, applicants were required to provide assurance to the Secretary of Health and Human Services that state law authorizes the statewide cancer registry. This proposed legislation would provide such authorization to maintain the cancer registry as it currently exists.

The North Dakota Cancer Registry is a statewide central registry system that collects incidence and mortality data on all North Dakota residents who are diagnosed and treated for cancer either within or outside the state. Its purpose is to support all aspects of cancer prevention and control (prevention, screening, diagnosis, treatment, rehabilitation and quality of life) by providing quality data and summary statistics. The Cancer Registry supports local public health and health-care providers, agencies and facilities by following cancer incidence and treatment trends, facilitating rapid reporting of cancer and providing accurate cancer data in report formats.

The attached program brochure describes the state Cancer Registry. I would like to take a few moments to describe how the Cancer Registry operates.

When a physician diagnoses cancer, that incident is reported in a patient's medical record. At the larger hospitals in North Dakota, a hospital cancer registry collects information about that cancer incident and enters it into a database in the form of an abstract. On a regular basis, the hospital reports new cancer incidents to the state central registry via an electronic download to a central database. In small hospitals

and independent physician offices, local registries do not exist. In those cases, a staff person in the office or medical records department periodically sends key information from the medical record of a cancer patient to the state Cancer Registry. The state Cancer Registry also receives abstracts, test results and partial medical record information from other facilities, such as outpatient surgical centers, clinics, pathology laboratories, treatment centers; from death certificates; and from central registries in other states.

If partial information is provided, contact is made with the agency or facility to retrieve any missing data elements. If necessary, a staff person travels to the facility to gather the needed information. During 2004, staff traveled to 18 locations in the state for this purpose.

When the data reaches the state Cancer Registry, it is entered into a privacy-protected database. The registry uses a software program to check the validity of data in the numerous fields against a set of acceptable codes. In addition, a staff person who is an expert in quality control reviews data visually.

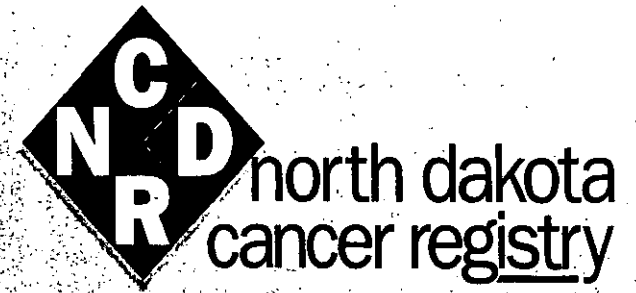
Each year, state Cancer Registry data is submitted to three major national organizations – the North American Association of Central Cancer Registries, the Centers for Disease Control and Prevention and the Central Brain Tumor Registry of the United States. Each month, the state Cancer Registry processes five to 10 requests for data from citizens of North Dakota, health-care providers, researchers, health-care organizations and others. Federal and state laws protect confidential medical information; therefore, only aggregate data is released and/or published.

Cancer Registry data is used in numerous ways, including:

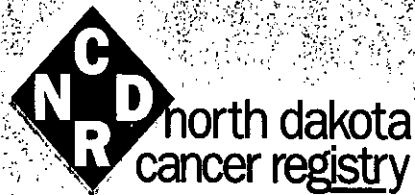
- Analyzing the burden of cancer in North Dakota.
- Identifying how many residents are diagnosed with cancers.
- Naming the most common types of cancer in North Dakota.
- Recognizing the deadliest cancers in the state.
- Studying trends in cancer treatment.
- Targeting efforts with cancer education, prevention and screening.

This proposed legislation will meet the requirements of the Federal law and allows the North Dakota Department of Health to maintain the operations of the state Cancer Registry. There is no additional fiscal effect and there would be no change in current practice.

This concludes my testimony. I am happy to answer any questions you may have.



The North Dakota Cancer Registry (NDCR) is a statewide cancer registry that collects incidence and mortality data on all North Dakota residents who are diagnosed and treated for cancer either within or outside the state. The purpose of the state central cancer registry is to support cancer control by targeting, monitoring and evaluating programs that promote early detection, diagnosis and treatment of cancer. The NDCR supports local health care agencies by providing summary statistics on the distribution of cancer cases, following cancer incidence and treatment trends, facilitating rapid reporting of cancer, and providing accurate cancer data for cancer-related reports.



North Dakota Department of Health
Division of Health Promotion
North Dakota Cancer Registry
600 E. Blvd. Ave., Dept. 301
Bismarck, N.D. 58505-0200
Telephone: 701.328.2333
800.280.5512 (in state only)
Fax: 701.328.2360

Web: www.health.state.nd.us/cancerregistry



Source of Quality Cancer
Incidence and Mortality Data



North Dakota Department of Health

What Is a Cancer Registry?

The North Dakota Cancer Registry (NDCR) – a statewide, population-based cancer registry that collects incidence and mortality data on residents of North Dakota – was established in 1994. Previously, cancer statistical information was available only through analysis of death certificates.

In 1996, the North Dakota Health Council amended the Administrative Rules to include cancer as a reportable disease. Data collection of newly diagnosed cancers began in January 1997. The collection of newly diagnosed cancers enables the NDCR to:

- Analyze the overall picture of cancer in North Dakota.
- Identify how many residents are diagnosed with cancer.
- Name the most common type of cancer.
- Recognize the deadliest cancers and if any area of North Dakota has lower or higher cancer rates.
- Study trends and improve cancer education, prevention and cancer screening.

Reportable Cancers

All in-situ or malignant cancers are reportable. This includes adenocarcinoma, carcinoma, leukemia, lymphoma, melanoma and sarcoma. All benign cancers of the central nervous system, pituitary gland, pineal gland and craniopharyngeal duct also are reportable. Basal and squamous cell carcinoma of the skin or carcinoma in-situ of the cervix is not collected.

Data Collection

Each hospital, outpatient surgical center, clinic, pathology laboratory, radiation or oncology treatment center and physician office is required to submit data, including treatment on newly diagnosed cancers, to the state central cancer registry within six months of diagnosis. Other sources of data include death certificates and cancer registries from other states.

What Type of Information Is Collected?

The registry collects only cancer-related information. This information can be sorted into four categories. *Demographic* includes the cancer patient's name, age, sex, race, ethnic background, marital status, birth-place, residence and occupation. *Administrative* includes the date the cancer was diagnosed and the source of the information. *Diagnostic* includes the type of cancer, the location of the cancer, the size of the cancer and the spread of the disease. *First course of treatment* includes all cancer treatment received.

Data Confidentiality

Federal and state laws protect confidential medical information. Only aggregate data are published.

Why Collect Identifying Information?

Patient identifiers are necessary because some cancer cases reported are diagnosed

and/or treated at several facilities. This means that duplicate records are received at the state central registry. Patient identifiers assist the registry staff in determining whether a case has been submitted previously and also allows for a complete cancer record from all reporting sources.

Quality Control

To assure accurate, complete and reliable data, the NDCR uses an EDITS software program that checks the validity of the data in the various data fields against a set of acceptable codes. Data validity also is verified by visual review of submitted records, external audits conducted by the Centers for Disease Control and Prevention and internal case-finding and reabstracting audits. Inaccurate information is reviewed and revised as necessary.

Health Insurance Portability and Accountability Act

The North Dakota Cancer Registry, part of the North Dakota Department of Health, is authorized by law to collect cancer information for the purpose of preventing or controlling disease and to conduct public health surveillance, public health investigations and interventions. The Health Insurance Portability and Accountability Act (HIPAA) permits covered entities to disclose protected health information without individual authorization to public health authorities such as state health departments.

North Dakota Cancer Coalition

January 11, 2005

Dear Madam Chair and Members of the House Human Services Committee:

I am writing to you as the Chairman of the North Dakota Cancer Coalition in support of House Bill 1117. Our Coalition consists of several healthcare organizations throughout our state involved in prevention, detection, treatment, and surveillance of cancer. Other members of the Coalition include the Health Department, American Cancer Society, North Dakota Medical Association, and the University of North Dakota to mention a few.

Our many members are all stakeholders in some form or another in the fight against cancer. Our primary goal is to decrease the incidence and death rate due to cancer in our state. The Coalition also has the long-term goals of bringing state-of-the-art cancer therapy to all citizens of North Dakota.

To accomplish our goals objectively requires good quality cancer data and statistics. This information is readily available to our organization through the North Dakota Cancer Registry. The purpose of the registry system is to collect incidence and mortality statistics on the residents of North Dakota who are diagnosed and treated for cancer.

In order to improve our efforts of cancer prevention, early detection, appropriate therapy and follow-up throughout our state, a centralized cancer registry is critical. This will enable us to understand the burden of cancer in North Dakota and identify trends in diagnosis and treatment of cancer. Thus, enabling us to target our efforts to decrease cancer incidence and mortality.

This proposed legislation would fulfill a continued essential function in the tracking of cancer in our state and for future planning. Thank you for your time and consideration.

Sincerely,

THIS DOCUMENT ELECTRONICALLY SIGNED BY KEVIN B. COLLINS M.D.
1/10/05.

Kevin B. Collins, M.D.

KBC/sap

Testimony

House Bill 1117

Senate Human Services Committee

Monday, February 14, 2005

North Dakota Department of Health

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