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 DATE PREPARED: February 09, 2020  
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**LB 1138**

Revision: 00

**FISCAL NOTE**  
**LEGISLATIVE FISCAL ANALYST ESTIMATE**

<b>ESTIMATE OF FISCAL IMPACT – STATE AGENCIES (See narrative for political subdivision estimates)</b>				
	<b>FY 2020-21</b>		<b>FY 2021-22</b>	
	<b>EXPENDITURES</b>	<b>REVENUE</b>	<b>EXPENDITURES</b>	<b>REVENUE</b>
GENERAL FUNDS	\$1,443,820		\$863,820	
CASH FUNDS				
FEDERAL FUNDS				
OTHER FUNDS				
<b>TOTAL FUNDS</b>	<b>\$1,443,820</b>		<b>\$863,820</b>	

**Any Fiscal Notes received from state agencies and political subdivisions are attached following the Legislative Fiscal Analyst Estimate.**

This bill requires the establishment of a dementia registry. The registry will include a record of cases of dementia that occur within the State and information concerning those cases that the Department of Health and Human Services determines necessary and appropriate to provide a basic source of information for further scientific and medical research. Information on individuals would be confidential.

The current cancer registry costs \$3.7 million annually. The department would develop and use an application to enable medical providers to send the required information for the registry to the department. Contractual and software costs would be \$1,090,000 in FY 2021 and \$520,000 in FY 2022. The department indicates five additional employees would be needed. Those include two informatics specialists, an epidemiology surveillance coordinator and a program specialist. The personnel and operating costs would be \$353,820 in FY 2021 and \$343,820 in FY 2022.

<b>ADMINISTRATIVE SERVICES STATE BUDGET DIVISION: REVIEW OF AGENCY &amp; POLT. SUB. RESPONSE</b>		
LB: 1138 AM:	AGENCY/POLT. SUB: Department of Health and Human Services (DHHS)	
REVIEWED BY: Elton Larson	DATE: 2/7/2020	PHONE: (402) 471-4173
COMMENTS: No basis to disagree with DHHS analysis and estimate of fiscal impact.		

**ESTIMATE PROVIDED BY STATE AGENCY OR POLITICAL SUBDIVISION**

State Agency or Political Subdivision Name:(2) Department of Health and Human Services

Prepared by: (3) Mike Michalski

Date Prepared 1-24-2020

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	<u>FY 2020-2021</u>		<u>FY 2021-2022</u>	
	EXPENDITURES	REVENUE	EXPENDITURES	REVENUE
<b>GENERAL FUNDS</b>	\$1,491,709	\$0	\$921,710	\$0
<b>CASH FUNDS</b>				
<b>FEDERAL FUNDS</b>				
<b>OTHER FUNDS</b>				
<b>TOTAL FUNDS</b>	\$1,491,709	\$0	\$921,710	\$0

Return by date specified or 72 hours prior to public hearing, whichever is earlier.

**Explanation of Estimate:**

LB 1138 establishes a dementia registry which is to be created and maintained by the Department of Health and Human Services (DHHS). LB 1138 specifies duties and guidelines for data collection and data sharing. An annual report of statistical information is to be issued and available for public access. DHHS is to promote awareness and participation in the dementia registry to medical professionals and facilities across the State of Nebraska.

This estimate is based upon statistical data for Alzheimer’s and dementia related illness as published in the 2019 Alzheimer’s Disease Facts and Figures by the Alzheimer’s Association with estimates on figures for Nebraska. The number of persons estimated to be living with dementia in Nebraska is currently 34,000 and the projected number in 2025 increases to 40,000 persons. Approximately 7,000 of those affected by these diseases die each year in Nebraska. Therefore, continual updating of this registry will be required.

LB 1138 will require patient data collection and exchange from the medical community on dementia related illnesses. DHHS would create an application that will automatically extract the required data from health care provider and facility software programs and send it electronically to the current health information exchange network for transmission to the DHHS Dementia Registry for storage, analysis and compilation of statistics.

Resources would be needed in order to design, build, test and implement a dementia registry. Due to similarities, this estimate models expenses based on the historical costs to create and maintain the Parkinson’s Disease Registry. Development timeline is approximately two (2) years to full operation from contractual executions. Developmental costs are listed under FY 2020-2021 and are estimated as follows:

1. Employ one (1) contract employee to fulfill the role of Project Manager to lead and coordinate all activities related to development and deployment of the Dementia Registry including budget tracking, creating tasks and timelines for project activities, assigning resources, monitoring progress and working to remove barriers, and keeping stakeholders informed. DHHS maintains a contract which would be able to supply this new project manager.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
Project manager annual contract cost – 2 years	\$135,000	\$135,000

2. Contract with software vendor to develop application functionality, database, and reporting infrastructure. Monitors system performance, troubleshooting as well as developing a test, training and production system.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
Vendor software contract initial startup cost	\$575,000	\$0
Vendor software annual maintenance - recurring	\$0	\$200,000

- Contract with current HIE vendor to create a common link for facility reporting to the HIE and migrate data received to the appropriate DHHS programs.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
HIE vendor data connection initial startup cost	\$380,000	\$0
Vendor annual maintenance fee - recurring	\$0	\$185,000

Additional developmental costs that will also be recurring costs are estimated as follows:

- Employ an additional two (2.0) FTEs to serve as Informatics Specialists. The duties of the Informatics Specialists would be to assist in system design and testing, assist with identified issue resolution, perform regression testing, monitor incoming data queues and resolve failed data transactions, assist reporting entities in data technical specification set up and transmission, ensure data accuracy and completeness, and provide initial training to reporting facilities. The ongoing duties would be to assess the validity and accuracy of data being received, continue support of system collection for evolving research needs, enhance system functionality and reporting capabilities, work with new reporting facilities in deploying the use of the electronic data exchange, train end users on site and coordinate the ongoing maintenance and updates to the system.

Academic degrees in Health Informatics have been an educational offering for many years. This is a special area of study combining life sciences, statistics and information technology. As the current state classification system lacks a close fit to all of these job duties specific to health data collection systems, this estimate is based on a typical market entry base salary of around \$28.875 per hour.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
(2) Informatics Specialists annual base salary	\$120,120	\$120,120
Paid Benefits	\$ 38,534	\$ 38,534
<u>Operating Costs</u>	<u>\$ 51,721</u>	<u>\$ 51,721</u>
Total Costs	\$210,375	\$210,375

- Employ an additional one (1.0) FTE Epidemiology Surveillance Coordinator to collaborate with the development team and to administer the complex dementia epidemiological surveillance system. Recurring duties would be to design and conduct related epidemiological studies involving complex data sets, multiple medical conditions, linking to multiple additional data sets and using sophisticated statistical analytical software. Interprets, analyzes and disseminates epidemiological reports to recommend intervention measures to promote the prevention, treatment and potential cure of this disease. Coordinates with physicians, public health departments, medical facilities, and state agencies to educate and engage in dementia surveillance and data usage.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
Epidemiology Surveillance Coordinator	\$ 61,707	\$ 61,708
Paid Benefits	\$ 19,796	\$ 19,796
<u>Operating Costs</u>	<u>\$ 26,570</u>	<u>\$ 26,570</u>
Total Costs	\$108,073	\$108,073

- DHHS would also require an additional one (1.0) FTE for a Program Specialist to coordinate the development, administration and evaluation of the Dementia Registry; serving as a resource and consultant to provide technical assistance/advice to agency staff, clients and service providers; researching and developing program policy performing quality assurance analysis, and ensuring statutory compliance.

	<u>FY 2020-2021</u>	<u>FY2021-2022</u>
DHHS Program Specialist	\$ 47,540	\$ 47,540
Paid Benefits	\$ 15,251	\$ 15,251
<u>Operating Costs</u>	<u>\$ 20,470</u>	<u>\$ 20,470</u>
Total Costs	\$ 83,261	\$ 83,261

All of the additional FTEs would be organized under the existing Health Statistics Administrator for this section.

LB 1138 does not identify the source of funding for the Dementia Registry. DHHS would attempt to obtain federal funding, where possible. However, should such funding not be available or provide coverage for 100% of the cost, general funds would be needed to implement LB 1138.

<b>MAJOR OBJECTS OF EXPENDITURE</b>				
<b>PERSONAL SERVICES:</b>				
POSITION TITLE	NUMBER OF POSITIONS		2020-2021	2021-2022
	20-21	21-22	EXPENDITURES	EXPENDITURES
Informatics Specialist	2.0	2.0	\$ 120,120	\$ 120,120
Epidemiology Surveillance Coordinator H74932	1.0	1.0	\$61,707	\$61,707
DHHS Program Specialist	1.0	1.0	\$47,540	\$47,540
Benefits.....			\$73,581	\$73,581
Operating.....			\$1,188,761	\$618,761
Travel.....				
Capital Outlay.....				
Aid.....				
Capital Improvements.....				
<b>TOTAL.....</b>			<b>\$1,491,709</b>	<b>\$921,709</b>