

THE CANCER REGISTRY BILL, 2014

MEMORANDUM OF OBJECTS AND REASONS

This Bill provides for the mandatory reporting on incidence of cancers and brain tumours and establishes a cancer and brain tumour registry for the retention of the data collected.

Part 1 of the Bill contains preliminary provisions and is comprised of clauses 1 to 5. Clause 1 seeks to provide for the short title and commencement.

Clause 2 provides for the definition of terms used in the legislation.

Clause 3 provides for the establishment of the Cancer Registry and sets out its purposes. The purposes of the Registry are, among other things, to compile a statistical record on the incidence of cancer and brain tumours and to provide data that will facilitate programme planning for research into cancer and brain tumours and the prevention of them.

Clause 4 provides for the appointment of the Cancer Registry Board and the constitution and procedure of the Board.

Clause 5 provides for the appointment of a registrar who will be responsible for the operation of the Cancer Registry.

Part 2 of the Bill contains provisions relating to the reporting of incidences of cancer and brain tumours and is comprised of clauses 6 to 10. Clause 6 mandates that the person in charge of a health care facility that carries out a test that indicates the presence of cancer or a brain tumour in any person shall report the result of the test to the Cancer Registry within 45 days of the receipt of the results. Similarly, where a post mortem examination indicates the presence of cancer or a brain tumour in a deceased person, the examiner shall make a report of that finding to the Registry.

Clause 7 provides that the Registry may require any person whom it reasonably believes has any data required to complete a report to provide the data within such time period and in such form as the Registry may specify by written notice.

Clause 8 provides for the format in which reporting to the Registry should be carried out. Reports may be made in a written document, in electronic form or by direct input of data into the Registry's database.

Clause 9 provides immunity against civil or criminal proceedings for persons who provide data in accordance with this Law.

Clause 10 provides that any data provided to or received by the Cancer Registry shall be kept confidential and disclosed only to persons or authorities concerned with the Registry's purposes.

Clause 11 prohibits the use of any data collected from being utilised in determining whether life insurance, health insurance, employment or similar benefit will be provided to an individual.

Part 3 of the Bill contains miscellaneous provisions and is comprised of clauses 12 to 15. Clause 12 provides for the offences of failing to comply with the reporting requirements of the legislation at sections 6 and 7(2) and knowingly supplying data that is false or misleading.

Clause 13 states that any data collected in accordance with the legislation is an exempt record for the purposes of the Freedom of Information Law, 2007.

Clause 14 provides that the Cabinet may by order amend section 8 and Schedule 2 with regard to the format and the substance of the report to the Cancer Registry.

Clause 15 empowers the Cabinet to make regulations to, among other things, exclude any cancer from the reporting requirements set out in this Law, provide for the setting up of systems to restrict access to any data collected and generally for the better carrying out of the objects and purposes of this Law.

THE CANCER REGISTRY BILL, 2014

ARRANGEMENT OF CLAUSES

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**PART 2 - REPORTING OF CANCER AND
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CAYMAN ISLANDS

**A BILL FOR A LAW TO PROVIDE FOR THE MANDATORY
REPORTING ON THE INCIDENCE OF CANCERS AND BRAIN
TUMOURS; THE ESTABLISHMENT OF A CANCER AND BRAIN
TUMOUR REGISTRY; AND FOR INCIDENTAL AND CONNECTED
PURPOSES**

ENACTED by the Legislature of the Cayman Islands.

PART 1 - PRELIMINARY

1. (1) This Law may be cited as the Cancer Registry Law, 2014.

Short title and
commencement

(2) This Law shall come into force on such date as the Cabinet may by Order appoint and different dates may be appointed for different provisions of this Law.

2. In this Law -

Interpretation

“the Board” means the Cancer Registry Board established under section 4 of this Law;

“brain tumour” means a growth of cells in the brain that multiply in an abnormal and uncontrollable way and may be [malignant or benign] ~~[cancerous or non-cancerous]~~;

“cancer” means -

~~(a)~~—a malignant growth of human tissue that, if unchecked, is likely to spread to adjacent tissue or beyond its place of origin and may have the propensity to recur including ;

~~(b)~~(a) carcinoma-in-situ, myelodysplastic syndrome, carcinoma, sarcoma, including Kaposi’s sarcoma, any mixed tumour, leukaemia, any type of lymphoma and melanoma;

“Cancer Registry” means the registry established under section 3;

“dentist” means a person registered as such under the Health Practice Law (2013 Revision);

“examiner” means the person carrying out a post mortem examination under section 6(2);

“health care facility” has the same meaning as in the Health Practice Law (2013 Revision);

(2013 Revision) “medical doctor” means a person registered as such under the Health Practice Law (2013 Revision);

2002 Revision “Medical Officer of Health” has the meaning assigned to it by the Public Health Law (2002 Revision);

“Registrar” means the person appointed under section 5 of this Law;

“resident” means any person ~~—~~who has been residing in the Islands ~~for at least two years prior to the date of the relevant test except the holder of a temporary work permit under section 53 of the Immigration Law (2014 Revision);~~ and

“test” means any examination, scan or imaging study (including any examination of blood, cytological or tissue biopsy specimen or other material) that is carried out in any health care facility to determine the presence or absence of cancer or a brain tumour in any person, including a deceased person.

Cancer Registry 3. There shall be a registry known as the Cancer Registry for the purposes of -

- (a) compiling a statistical record of the incidence of cancer and brain tumours;
- (b) providing data that will facilitate research into cancer and brain tumours and the prevention of their occurrence; and
- (c) providing data on the incidence of cancer and brain tumours and any consequent mortality in the Islands,

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and shall be maintained by such funds as may from time to time be appropriated for the purpose of the Cancer Registry by the Legislative Assembly.

4. (1) There is established a Cancer Registry Board whose functions are to -
- (a) oversee the operations of the registry;
 - ~~(b) [put in place operational policies and guidelines for the operation of the registry and the collection, analysis and sharing of any data collected];~~
 - ~~(b)~~ appoint a Registrar;
 - ~~(c)~~ prepare and submit an annual report to the Minister on the activities of the registry, including regarding ~~{any trends or findings regarding cancer and brain tumours in the Islands and the operations of the registry};~~ and
 - ~~(d)~~ to make recommendations to the Minister regarding ~~{any trends or findings regarding cancer and brain tumours in the Islands}.~~

Establishment of Board

- (2) The constitution and procedure of the Board are set out in Schedule 1.

Schedule 1

5. (1) The Board may appoint at such remuneration and on such terms and conditions as it thinks fit, a suitable person as the Registrar who shall have charge and control of the Cancer Registry and shall under the guidance of the Medical Officer of Health, be responsible for the operation of ~~the Registry~~.

Registrar

- [(2) The Registrar shall -

- (a) put in place systems to collect the relevant data and maintain the confidentiality of data provided to the registry;
- (b) adhere to the quality assurance guidelines and duties;
- (c) under the guidance of the Medical Officer of Health, be responsible for carrying out data analysis and preparing statistical reports requested by the Cancer Registry Board;
- (d) participate in the establishment and documentation of clinical research protocols;
- (e) develop cancer registry-related data collection systems that meet the standards of the relevant accrediting and reporting agencies;
- (f) report periodically to the Cancer Registry Board on the operation of the quality assurance guidelines and the related duties;
- (g) ensure accuracy of data collected and consistency between the Cancer Registry's records and that of the records of participating health care organizations and medical doctors; and
- (h) be an advocate for the protection of health data.

(3) In the absence or inability of the Registrar to fulfil his duties, the Board may appoint the Medical Officer of Health or his designate to carry out the duties of the Registrar during the period of his absence or disability.]

PART 2 - REPORTING OF CANCER AND BRAIN TUMOURS

Reporting of cancer and brain tumours

6. (1) Where a test confirms the presence of cancer or a brain tumour in any resident of the Islands, including a resident who is deceased, ~~the person in charge of the health care facility where the test was carried out or that sent the specimen [or image] overseas for testing, the medical doctor or dentist who ordered the test~~ shall cause a report of that test result to be made to the Cancer Registry no later than 45 days after receipt of the results by the ~~health care facility~~ medical doctor or dentist.

(2) Where a post mortem examination indicates the presence of cancer or a brain tumour in a deceased resident, the examiner shall cause a report of that finding to be made to the Cancer Registry.

Schedule 2

(3) Every report under this section shall provide data as set out in Schedule 2.

(4) Where data required for inclusion in any report is unavailable at the time that the report is made or is otherwise not capable of being obtained -

- (a) the report shall indicate that the data is unavailable or not capable of being obtained; and
- (b) where the data subsequently becomes available, the person required to make the report shall, as soon as it is practicable, transmit that data to the Cancer Registry.

(5) A person is not required to make a report under this section where there is reason to believe that the presence of cancer or a brain tumour in a person has been reported already pursuant to this Law or any arrangements that may have been in place for reporting prior to the commencement of this Law.

Registrar may request further information

7. (1) Where a report made under section 6 is incomplete by reason that the person making the report does not have the data necessary to complete the report, the Registrar may, by notice in writing, require any person, being a medical doctor, a dentist, an examiner or the person in charge of a ~~hospital~~ health care facility, whom the Registrar reasonably believes has any of that data, to provide the specified data in accordance with this Law.

(2) Every person to whom a notice is addressed under this section and who has the requisite data specified in that notice, shall provide it within such time and in such form as may be specified in the notice.

8. A report including the data required in the Schedule 2 may be submitted either -

Format of reporting
Schedule 2

- (a) as a written document;
- (b) in electronic form by way of compact disc or other storage device; or
- (c) by direct input of data into a database maintained by the Registrar, such input being made by means of remote access to the database.

9. No proceedings, civil or criminal, shall lie against any person by reason of that person having made available data for the purposes of complying with the requirements of section 6 or section 7(2).

Immunity

10. (1) Data provided to and received by the Cancer Registry for the purposes of this Law shall be treated as confidential.

Confidentiality

(2) Data provided or received by the Cancer Registry shall, where authorized, be disclosed only to persons or authorities concerned with the purposes specified in section 3, and used by such persons or authorities only for those purposes.

(3) Any person who discloses data in the Cancer Registry without authority commits an offence and shall be liable on summary conviction to a fine of ten thousand dollars.

[11. (1) Data collected in accordance with this Law shall not be utilised by any person in determining whether life insurance, health insurance, employment or similar benefit will be provided to an individual.]

Prohibited uses of data

(2) Any person who uses data collected in accordance with this Law for the purposes set out in subsection (1) commits an offence and shall be liable on summary conviction to a fine of fifteen thousand dollars.

PART 3 - MISCELLANEOUS PROVISIONS

12. Any person who -

Offences

- (a) fails, without reasonable excuse, to comply with the requirements of section 6 or section 7(2); or
- (b) knowingly supplies data that is false or misleading in the purported compliance with section 6 or section 7(2),

commits an offence and is liable on summary conviction to a fine of one thousand dollars.

Exempt record
(Law 10 of 2007)

13. Any data collected in accordance with this Law is an exempt record for the purposes of the Freedom of Information Law, 2007.

Amendments

14. The Cabinet may, by order, amend section 8 and Schedule 2 to this Law with respect to the format and substance of the report.

Regulations

15. The Cabinet may make regulations prescribing all matters that are required or permitted by this Law to be prescribed, or are necessary or convenient to be prescribed for giving effect to the purposes of this Law and, in particular -

- (a) declaring any type of cancer to be a cancer to which this Law does not apply;
- (b) providing for systems to restrict access to and protect data collected;
- (c) providing for the persons or authorities with whom data collected in the Cancer Registry may be shared and the conditions on which the data is shared; and
- (d) prescribing any forms to be used for the purposes of this Law.

Schedule 1

(Section 4)

Constitution and Procedure of the Cancer Registry Board

Composition of the
Board

1. (1) The Board consists of -

- ~~(a) the Chairman of the Health Services Authority;~~
- ~~(b)~~ the Chief Executive Officer of the Health Services Authority;
- ~~(c)~~ the Chairman of the Cayman Islands Cancer Society;
- ~~(d)~~ the Medical Director of the Health Services Authority;
- ~~(e)~~ the Medical Director of the Cayman Islands Cancer Society;
- ~~(f)~~ the Senior Pathologist at the Health Services Authority;
- ~~(g)~~ the Medical Officer of Health; ~~and~~
- (g) a medical doctor or dentist who is not an employee of the Health Services Authority;
- (h) a member of the public who is not registered as a practitioner under the Health Practice Law (2013 Revision);
- (h) an attorney-at-law; and
- (j) the Registrar, ex officio, who shall be secretary to the Board.

(2) The chairman and the deputy chairman of the Board shall be appointed by the Cabinet from the persons listed in paragraph 1.

(3) The Cabinet shall state in the appointment the period of time for which the chairman and the deputy chairman shall serve in those positions and they shall hold and vacate the position in accordance with the terms of their appointment.

(4) The Cabinet shall cause notice of such appointments to be published in the Gazette.

(5) ~~The Cabinet may appoint a secretary to the Board who~~The secretary to the Board shall record and keep all minutes of the meetings, proceedings and decisions of the Board but ~~the secretary shall not be a member of the Board and shall~~ not have a right to vote.

(6) In the absence of the chairman, the deputy chairman shall preside and perform the functions of the chairman.

2. (1) The Board shall meet at least once in every four calendar months and it may decide on its own procedures, except so far as its procedures may be prescribed by this Law or regulations made hereunder.

Procedure of the Board

(2) At every meeting of the Board a quorum shall consist of four members including the chairman, and decisions shall be adopted by a simple majority of the votes of members present and voting except that in the case of an equality of votes the chairman shall have a casting vote.

(3) The Board may act notwithstanding that a vacancy exists among the members.

(4) The deliberations of the Board shall be confidential but the Board shall cause any decision which affects members of the public to be published in the Gazette, on relevant websites or in a newspaper published in the Islands.

(5) Where a member of the Board has any personal or pecuniary interest, direct or indirect, in any matter that is to be determined by the Board, he shall, if present at the meeting of the Board at which such matter is to be determined, as soon as practicable after the commencement thereof, disclose the fact and remove himself from the meeting, and he shall not take part in the consideration or discussion of such matter or vote on any question with respect thereto.

(6) Minutes of each meeting shall be kept in a proper form and shall be confirmed by the chairman as soon as practicable at a subsequent meeting, and a copy of the minutes as confirmed by the chairman shall be sent to the Minister with responsibility for health.

Schedule 2

(Section 8)

Test Report

- (1) Every report shall contain the following data -
- (a) the full name and business address of the person or persons who carried out the test to which this report relates;
 - (b) the full name and business address of the medical doctor ~~or other registered practitioner, dentist or examiner~~ who requested the test;
 - (c) in relation to the person on whom the test was carried out -
 - (i) name, alias or any other names that he is known by or may have been known by;
 - (ii) date of birth;
 - (iii) gender;
 - (iv) ethnicity;
 - (v) full address, including the mailing address;
 - (vi) occupation;
 - (vii) nationality; and
 - (viii) length of residence in the Islands;
 - (d) in relation to the test carried out -
 - (i) the category set out below into which the test falls -
 - (aa) histology of the primary lesion or, in the absence of a known primary lesion, the metastasis;
 - (bb) cytology or haematology, or both;
 - (cc) specific biochemical or immunological test, or both; or
 - (dd) autopsy with concurrent or previous histology;
 - (ii) a description of the anatomical site from which the sample was obtained, as indicated on the form requesting the test; and
 - (iii) whether that site is the primary site or the secondary site of the cancer or the brain tumour indicated by the test;
 - (e) in relation to the cancer or the brain tumour indicated by the test to which the report relates -

- (i) a full description of the pathological nature of the cancer or brain tumour;
 - (ii) in the case of malignant melanoma of the skin -
 - (aa) the thickness of the tumour, measured in accordance with “Breslow’s method”; and
 - (bb) the extent of tumour invasion, expressed by reference to “Clark’s levels”; and
 - (iii) where available, the stage of the cancer (other than for lymphoma, leukaemia, and malignant melanoma of the skin) or malignant brain tumour.
- (2) Where any data required for a report is unavailable at the time of reporting or the data is unobtainable -
- (a) the report shall indicate that the data is unavailable or, as the case may be, unobtainable; and
 - (b) if that data subsequently becomes available, the person required to make the report shall, as soon as practicable, transmit that data to the Cancer Registry.

Passed by the Legislative Assembly the day of , 2014.

Speaker.

Clerk of the Legislative Assembly.