

HEALTH (WESTERN AUSTRALIAN CANCER REGISTER) REGULATIONS 2011

The Western Australian Cancer Registry is a population-based health data repository which receives and collates information received in accordance with the (WA) Health (Notification Of Cancer) Regulations 1981. The Regulations were last amended in 1996.

Legislative change may be required to ensure that notification systems allow data collections to keep abreast of current thinking about the diseases of interest, and terminology, as well as to provide more complete notification and legal protection for those who do supply information.

A process to update the Regulations was commenced in 2005 and has involved significant consultation in the earlier stages, followed by long periods of work on legal terminology. The end result has been the recent Gazettal of a new set of regulations, to be known as the **HEALTH (WESTERN AUSTRALIAN CANCER REGISTER) REGULATIONS 2011**. The new regulations will come into force, on 10th June 2011.

OVERVIEW OF CHANGES

The mainstay of both old and new versions of the Regulations, is the supply of copies of pathology reports concerning relevant conditions. However, there have been other notification sources including radiation oncologists, and ophthalmologists and hospitals have also been added to improve the notification of non-pathologically diagnosed conditions.

The main changes incorporated in the new Regulations, which were envisaged during the early stages of the process, can be summarized as follows:

(1) Inclusion of entities in the scope of the notification requirement:

- All carcinoid & neuroendocrine tumours, gastrointestinal stromal; tumours, adrenal phaeochromocytomas and other paragangliomas of the autonomic nervous system.
- Borderline or “uncertain behaviour” ovarian and CNS tumours.
(Primary SCC and BCC of the skin are still excluded whether in situ or invasive; all other in situ or invasive malignancies, and benign CNS neoplasms are still included.)

- The lymphohaematopoietic neoplasms have been itemized to further clarify the list, which does include some conditions that were not universally regarded as malignant until the WHO classification revision of 2000, and which may still not be known to be of interest by some pathologists and haematologists.

The list includes but is not limited to, *leukaemia; lymphoma; plasma cell, mast cell or histiocytic neoplasm; myelodysplastic syndrome; refractory anaemia; refractory cytopaenia; chronic myeloproliferative disorder; polycythaemia rubra vera; idiopathic and essential thrombocythaemia; myelofibrosis; myelosclerosis; and any other immunoproliferative, lymphoproliferative or myeloproliferative disorder.*

(2) Provision for the pro-active notification by ophthalmologists, of clinically-diagnosed ocular melanoma (often treated by radiation prior to any surgery);

(3) Provision for the mandatory reporting by hospitals, of cancers not known to be otherwise notified (a requirement that has been in place, and in a more demanding form, in all other States for many years). It is hoped that this will better capture information particularly concerning persons who do NOT have pathology results.

(4) Removal of the provision for payment for notifications (a provision that has not existed elsewhere in Australia for at least the last 15 years.)

(5) Inclusion of cancer Stage information in the Schedule of data items that can be required from Doctors and Hospitals; enabling the registry ultimately to provide more meaningful survival analyses and other data.

(6) Removal of a requirement for information on marital status and occupation, and replacing a requirement for "Race" with Indigenous Status;

Other changes made later in the process as result of feedback or changes in the legislative environment, include:

(7) Adding clinical biochemists to the notifiers, as the spectrum of diagnostic tests widens.

(8) The Regulations for the first time formally establish a WA Cancer Register, and set out the purposes to which information may be put, and the restrictions on use of identifying information. These "disclosure provisions" expressly permit the use of information in all the ways it is currently used. They provide a clearer legal protection for Registry staff; whereas the earlier parts of the Regulations provide improved protection for those who provide information to the Registry. Both define the rules clearly enough that the protection of individuals' privacy within the Registry should offset any perception of breach of privacy in complying with the new notification requirements.

(9) The Regulations specifically allow the release of information "in a case of urgency, to assist in the diagnosis, staging or treatment of the person to whom the information relates, if it is not reasonably practicable to obtain the written consent of that person to the disclosure". This does mean that Registry copies of pathology reports can be made available to pathologists and treating doctors on request, without delay, where it would be of assistance. This has been policy for many years without incident but the process now has legal protection.

(10) Provision for the notification of "related reports" in a case of cancer. This is intended to allow laboratories to send to the Registry, reports such as histology on an axillary lymph node dissection, even when the results are negative; so that our information on nodal status is complete even when a dissection is done separately to a breast cancer excision.
