#### *NI Cancer Registry - Confidentiality of Cancer Registry Data Genetic Counselling*

The policy of the United Kingdom and Ireland Association of Cancer Registries (UKIACR) concerning the release of data for the purposes of genetic counselling requires that a named registered medical practitioner shall be responsible for the confidentiality, use and security of data (see below).

**Policy**

(i) Requests for cancer registry information from registered medical practitioners working in genetic counselling clinics concerning living family members, related to a proband undergoing counselling should be accompanied by a signed consent form obtained from each family member (or their legal guardian) about whom information is requested. The consent form should permit the release to the named registered medical practitioner of information relating to cancer from medical and hospital records. The consultant and, where possible, the general practitioner responsible for the family member should be informed about the data release.

Information regarding living cancer patients should not be released without their signed consent.

(ii) Information regarding patients known to have died can be released to a registered medical practitioner for counselling purposes, upon request, without consent.

(iii) Registered medical practitioners receiving cancer registry information must undertake to maintain the confidentiality of the data, keep it securely and release it only for counselling purposes. The duty of confidentiality relating to medical information extends beyond death and the above requirements must be adhered to for information relating to both living and deceased patients.

(iv) The information released for counselling purposes should consist of the minimum necessary to achieve the objectives required. In normal circumstances this would comprise; name, address, date of birth, date of diagnosis, cancer site and histology, name and hospital of managing consultant and (for living patients) name and address of GP.

**Name of Medical Practitioner responsible:**

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I declare that I understand and agree to act in accordance with the UKIACR policy.

Signature ............................................................................................................... Date .......................................................

Name of recipient if not the medical practitioner whose name is given above.

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