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Attachment - C

Nova Scotia Atlee Perinatal Database Data Management Principles

The Nova Scotia Atlee Perinatal Database (NSAPD) contains population-based perinatal data from 1988 onwards. The success of the NSAPD depends on the continued support of senior leaders, health care managers, health information professionals and health care providers associated with facilities that provide maternal and newborn services. The intent of this document is to identify the legislative framework for the NSAPD and the key principles that:

- a) ensure, to the confidentiality of personal health information held in the NSAPD, and
- b) maintain the integrity and security of all data contained in the NSAPD.

Senior leaders, clinical and health information managers, and care providers all contribute to the District Health Authority (DHA)/facility perinatal care system. For the purposes of this document, these units are referred to as DHAs/facilities. Communication and decision-making structures that involve key disciplines and individuals (e.g. Perinatal or Maternal-Child Committee or equivalent) are important vehicles for inter-professional communication. These structures support the principles outlined in this document.

1. The *Personal Health Information Act (PHIA)* governs the collection, use, disclosure, retention, disposal and destruction of personal health information in Nova Scotia. The *Act* recognizes both the right of individuals to protect their personal health information and the need to collect, use and disclose personal health information to provide, support and manage health care. *PHIA* is enforceable in the courts of Nova Scotia. Penalties may apply for offences under the *Act*. <http://novascotia.ca/dhw/phia/PHIA-legislation.asp>
2. The Reproductive Care Program (RCP) is one of a number of provincial programs of the Nova Scotia Department of Health & Wellness. As a provincial program, RCP is the custodian for the Nova Scotia Atlee Perinatal Database, on behalf of the Minister of Health & Wellness. Custodians under *PHIA* are subject to independent oversight by the provincial Review Officer.
3. Although collection, use and disclosure of personal health information without consent, under section 38 (g) of the *Act*, is permitted for planning and management of the health system, and under 38 (f) to assist DHAs/facilities in ensuring quality or standards of care, they must understand and support the ways in which data they contribute to the

NSAPD are utilized at local, regional and provincial levels. The most common uses include but are not limited to:

- a. annual provincial reports of population characteristics and outcomes;
 - b. provincial reports focused on quality initiatives;
 - c. temporal trends for population health indicators displayed by DHA of residence;
 - d. standardized facility-specific reports available to the facility in which the events occurred;
 - e. monitoring progress towards key performance benchmarks;
 - f. requests for aggregate data in which no individual, distinct population group, health care provider or facility can be identified;
 - g. data files for approved research projects (requires both Data Access Committee and Research Ethics Board Approval, as delineated in sections 53 to 60 of the *Act*).
4. Protection of personal health information is required by *PHIA*. The legislation and accompanying regulations and policies outline the mechanisms that must be in place to protect individual privacy. Confidentiality of caregiver and facility specific information is not addressed by *PHIA* but is an important operational prescript for managing the NSAPD.
 5. Data that could identify a facility or care provider will not be released by RCP without the knowledge and agreement of the DHA/facility or care provider, unless there is a legal or administrative order authorized by the Minister to do so. DHA/facility approval must include approval from individuals involved in care provision and administration at that facility. Copies of facility-specific information will be provided to the individuals who have given approval, prior to data release.

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