**At A Glance**

**Monthly highlights of ICES research findings for stakeholders**

### Privacy concerns hinder development of useful medical registries needed for improved care


**Issue**

The development and usefulness of consent-based registries are limited by numerous difficulties associated with obtaining informed consent for medical registry research, which benefits patient care.

**Study**

Examined the effectiveness of a comprehensive attempt to obtain informed consent from stroke patients participating in the Registry of the Canadian Stroke Network, a registry comprised of 20 hospital stroke centres across eight provinces. The study tracked the overall participation rate (consent rate among all potential stroke patients at each stroke centre) and the characteristics of consenting patients.

**Key Findings**

- The overall participation rate reached no more than 51% during the study period.
- Barriers to obtaining consent included: patients dying or leaving hospital before being approached for consent; patients not admitted to hospital, cognitively impaired patients with no surrogate decision maker; and patients who could not speak English or French.
- Difficulties with obtaining consent resulted in major sample biases, with enrolled patients being younger and healthier than those not enrolled.

**Implications**

Privacy legislation needs to balance the importance of protecting the privacy of personal health information with the benefits to society that can be achieved from anonymous clinical registry studies that have not obtained patient consent, but have used appropriate safeguards to protect patient confidentiality.

### Infant hospitalizations impacted by family’s health


**Issue**

There are no studies that examine how family characteristics affect an infant’s rate of hospitalization, although evidence shows that such rates are not due to differences in health alone.

**Study**

Data on more than 332,000 Canadian infants, aged 12 to 24 months, were used to examine the contribution of family socio-demographic (e.g. incomes) and psychodynamic factors (e.g. maternal health) to the risk of hospitalization among these infants.

**Key Findings**

Overall, 11% of infants were hospitalized. Low income, single parenthood, and maternal depression were all significantly associated with hospitalizations.

**Implications**

Recognition and treatment of maternal depression may help to reduce hospitalizations rates in infants.

### Patients at high risk for stroke are under treated in Ontario


**Issue**

Despite published recommendations, the management of transient ischemic attacks (TIAs) in clinical practice is variable and often sub-optimal.

**Study**

Examined the management and outcomes of 371 TIA patients who came to the emergency departments (ED) of four regional hospital stroke centres in Ontario in 2000 (before the introduction of the Ontario Stroke Networks).

**Key Findings**

Of the three-quarters of TIA patients discharged from the ED, one in 20 had a stroke within 30 days of discharge. The results also showed that diagnostic tests and stroke prevention medications were underutilized in TIA patients, and that these patients were less likely than stroke patients to see a specialist while in the hospital.

**Implications**

TIAs should be approached with the same urgency as strokes. Patients should also be made aware of TIA symptoms and the need to seek immediate medical attention.
Study shows striking variation in the use of end-of-life care in U.S. hospitals

Issue
Although it is known that variation exists in the use of health resources for chronically ill patients across hospital regions in the U.S., it cannot be explained by patient preferences or rate of illness.

Study
Evaluated the use of health care resources in the last six months of life for patients admitted to 77 academic medical centres in the U.S., each with a reputation for providing high quality chronic care.

Key Findings
The following is a summary of the wide variation seen in the use of resources across the 77 centres:

- Inpatient days ranged from 9 to 27 days, and ICU days ranged from 2 to 10.
- Number of physician visits ranged from 18 to 76 visits.
- Percentage of patients seeing 10 or more physicians ranged from 17% to 59%.
- Hospice enrolment ranged from 11% to 44%.

In terms of the intensity of terminal care:

- The percentage of deaths occurring in hospital ranged from 16% to 56%.
- Deaths associated with a stay in the ICU ranged from 8% to 37%.

Implications
Despite having strong national reputations for clinical care, variation in resource utilization suggests that these organizations would benefit from participating in comparative studies of practice patterns, with a view to rationalizing the use of end-of-life care.

Rectal cancer patients treated at high-volume hospitals have better outcomes

Issue
The association between hospital volume, type of surgery, and survival for patients with rectal cancer is uncertain.

Study
Examined the permanent colostomy rate and 30-day and two-year mortality rate for more than 7,000 rectal cancer patients in California, USA who underwent surgical resection between 1994 and 1997.

Key Findings
The 30-day mortality rate was 1.7% among patients of high-volume hospitals and 4.6% among patients of the lowest volume hospitals. Two-year survival ranged from 85% in high-volume hospitals to 79% in the lowest volume category. Patients in the lowest volume quartile had a 7% increase in the absolute risk of permanent colostomy compared to those in the highest volume quartile.

Implications
Identifying processes of care that contribute to differences in permanent colostomy and survival rates between high- and low-volume hospitals may help improve patients’ outcomes in all hospitals.