Provincial Council for Maternal and Child Health

Retinopathy of Prematurity Work Group

Terms of Reference

Background/Context:

Building a brighter future for children begins by ensuring a good start to life, with access to appropriate Levels of Care for mothers and newborns in Ontario. We require an integrated and coordinated provincial system of maternal and neonatal services capable of delivering timely, equitable, accessible, high quality, evidence-based, family –centred care in an efficient and effective manner.

The Issue

One longstanding system issue involves the lack of timely and equitable access to high quality eye examination and treatment of retinopathy of prematurity (ROP). Those neonates most at risk for development of ROP are infants born at or below 30 weeks gestational age and/or under 1500 grams at birth. Infants born at higher birth weight may be recommended for eye examinations for ROP on discretion of the attending neonatologist because of significant systemic morbidities. At risk infants require eye examinations for detection of ROP starting at 31 weeks gestational age or 4 weeks after birth, whichever is later. These eye examinations should continue until either there is complete retinal vascularisation or clear evidence of regression of ROP (usually evident by 45 weeks gestational age) or evidence of progression of disease which requires treatment. Failure to examine and treat these vulnerable infants appropriately places the newborn at high risk for serious permanent vision impairment.

At risk children born in Modified Level III, Advanced Level II or Level II Units where screening services are intermittent or unavailable must be transported or transferred to centres that can provide ophthalmic examination service. Both situations have cost implications for the system, potential morbidity due to the transfer of the infant, and carry an emotional and, in the case of transfer, economic burden for the family. Newborns requiring eye examinations unavailable locally but whom otherwise do not require a Level III bassinet will block a scarce resource for a neonate in need of Level III care.

All treatment for ROP is provided only within a Paediatric Academic Health Sciences Centre.

At present, there is no incentive system in place for remote evaluation for assessment / detection of ROP, although the technology does exist and can provide a closer-to-home option for neonates.

Workgroup Purpose:

To assemble experts in the area of retinopathy of prematurity, administrators and practitioners in neonatal and paediatric care in order to recommend to the Provincial Council for Children's Health an implementation strategy for the province-wide roll-out of remote ROP examination.

Objectives:

1. Describe the current capacity for ROP examination of at risk newborns in Ontario
2. Identify gaps in ROP examination capacity
3. Design a pilot project for the purposes of evaluating remote ROP examination.
4. Recommend a pilot site or sites
5. Based on the results of the pilot, provide recommendations for implementation of a provincial system of remote ROP examination
6. Recommend clinical guidelines for eye examination to promote consistency between hospitals and standardization of practice

Membership:

The Work Group membership will be trans-disciplinary and the following areas of expertise will be represented:

Paediatric Ophthalmology

Neonatology

Paediatrics

Nursing

Administration

Reporting Relationship:

The Retinopathy of Prematruity Work Group will report to the Provincial Maternal-Newborn Advisory Committee of the Provincial Council for Children's Health.

Frequency of Meetings:

4 to 5 meeting, mostly via teleconference

Timeframe:

May 2008 to February 2009

Decision –Making Process:

Members share accountability for decisions. There should be open and direct communication based on honesty, respect and transparency, to ensure that all perspectives are heard. Decisions should be evidence or most promising practice based. Decision will be made by consensus whenever possible.