

Variations in mortality rates among Canadian NICUs — and anonymous reporting

Perhaps the greatest contribution of the Canadian Neonatal Network's recent report¹ is the debate it has initiated regarding institution identification in outcomes research. The accompanying commentary² by *CMAJ* editors states that the decision by the authors of the report not to name the participating hospitals was based on 2 factors — a prior guarantee not to link results to specific institutions, and the opinion that identification of the institutions may be misleading.

The first consideration is not the obstacle it may initially appear. The situation is not analogous to obtaining consent for patient information under a guarantee to protect privacy. An initial agreement not to disclose institutional identity could be revised by the participants should they agree that the public interest is promoted by lifting the veil of anonymity.

Although the merits of publishing league tables of mortality rates in neonatal intensive care units (NICUs) are debatable,³ insisting on anonymity may have led to loss of additional valuable information. One landmark study has demonstrated a relationship between patient volume and outcomes for level 3 NICUs⁴ above the threshold of an average daily census of 15 patients. Other studies have found similar associations in pediatric ICUs,⁵ or have failed to replicate these results for infants with very low birth weights.⁶ Investigation of volume–outcome relationships in Canadian NICUs would be a valuable contribution. In the study published in *CMAJ*, partial information discerned from the figures points to an apparent moderate relationship between overall volumes and adjusted mortality rates.¹ Obviously, the best and proper way to determine the existence and magnitude of any volume–outcome relationship is to analyze the data for specific subgroups of neonates and to directly test for the significance of a case-volume factor. This can be easily accomplished with the data available.

Reporting on a possible volume–

outcome relationship may not have been pursued in the Neonatal Network's report in view of the possible unmasking of individual units' identities. If that is the case, the study participants have, in the interest of maintaining anonymity, forgone the opportunity to provide valuable information to inform policy and planning. This silence does not serve the public interest and is not tenable given the double-doses of public funding that support this research — first for patient care, and second to support the research network. Although it may not be advisable to report the units' results in league-table format, shying away from any disclosure may have led to the loss of valuable information. In the future, not only should journals be unwilling to publish anonymous results,² but publicly accountable funders should also be unwilling to support research that favours researchers' interests over those of the public.

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[The authors respond:]

We agree with the *CMAJ* editors¹ and Antoni Basinski that public health care institutions should be transparent and accountable. However, we are

concerned about the editors' decision to not publish future research that does not name hospitals. A principal aim of the Canadian Neonatal Network is to develop evidence-based methods for evaluating outcomes and improving quality of care in the neonatal intensive care unit (NICU).²⁻⁵ Our research created an industry-wide risk-adjustment standard (Score for Neonatal Acute Physiology Version II, or SNAP-II),⁵⁻⁸ which permits valid comparison of NICU outcomes and is now used by hospitals and researchers in many countries. This research could not have been done without confidentiality provisions. Hospitals are naturally wary about giving *a priori* permission to name them when it is unclear at the outset whether the research will achieve its goal of creating a validated risk-adjustment instrument. Even the editors acknowledge the importance of honouring prior commitments. Contrary to the editors' concerns, SNAP-II actually enables regulators to ensure hospital transparency and accountability, and the irony of the *CMAJ* decision is that it directly penalizes and discourages research efforts like ours. Like other authors,^{9,10} Basinski himself acknowledges that there is no value in publishing league tables on NICU outcomes.

We are puzzled when the editors maintain that there is no evidence that the public acts inappropriately when this kind of information is released, while asserting that "for expectant parents and their physicians it might be important to know the identities of the institutions."¹ We also take issue with the editors' contention that research confidentiality decreases motivation for quality improvement. As part of our ongoing research program, participating hospitals have partnered with the Canadian Institutes of Health Research to co-fund a \$1.7 million study to develop an innovative evidence-based practice identification and change system for improving care in Canadian NICUs.

We would like to assure Basinski that anonymity has not led to a "loss of additional valuable information." His concern about identifying the causes of outcome variation is relevant, and this is integral to our research. We previ-

ously published evidence showing that the success of regionalization programs has meant that patient volume is not related to outcome variation in Canadian NICUs.^{8,11} We invite readers to visit our Web site (www.caneonet.org) and to read our 91 peer-reviewed publications to date on NICU outcomes and health-services related issues.

We have many more research findings to share with our health-care colleagues in Canada and elsewhere, and we regret that the *CMAJ* decision will force us to submit future manuscripts to leading foreign medical journals instead of *CMAJ*. The editors intended their comments to provoke debate. Now that they have made their point, we question the wisdom of a decision to ban future publication of high-quality research, without regard to science or academics, and in apparent disregard of the principles of peer review.

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The position taken in the recent commentary "What's in a name? Reporting data from public institutions" is thoughtful, provocative and, in an ideal world, one with which we would have no argument. In an ideal world, all research tools would already be fully validated, research-funded institutions would in any case be required to report routinely a wide variety of indicators on their performance, and the bodies to whom they were accountable (be it regions or provinces) would in turn be required to report to the public on the relative performance of their publicly funded institutions. Under such circumstances, there would be no question that a researcher should identify all organizations involved in his or her research. But we're not there yet, and we need to deal with reality.

At least 3 practical issues deserve to be highlighted. First is the validity of measurement tools.

As the commentary acknowledges, research involves the continuous development and refinement of new measurement and evaluation tools; each new instrument requires time and experience before it can be validated. Institutions

and practitioners involved in research using these nonvalidated instruments during the development and testing phases, may, understandably, not be comfortable with committing themselves a priori to being identified. The risk of misleading results should not be underestimated. One could cite a number of high-profile examples of the implications for institutions of "too-early" exposure. Thus, this seems a reasonable and defensible position for these institutions. Whether institutions would be prepared to participate in research without remaining anonymous if some acceptable and explicit validity criteria could be established is an interesting question (but one for which neither we, nor *CMAJ*, currently has answers).

The second issue relates to the grandfathering of existing agreements. Research that is already completed, or currently in progress, may have been initiated without expectations or understandings of the sort articulated in the *CMAJ* editorial. Hence, even if the issues raised in the first paragraph were all resolved, it seems only fair that these studies be "grandfathered" if that is the wish of the participating institutions. Until such time as the agencies that fund research require disclosure at the time of project approval, it is inappropriate for *CMAJ* to impose this expectation after the fact.

The third concern is the need to strengthen the requirements placed on publicly funded institutions. Our view is that this issue cannot be addressed narrowly, in isolation from the more general issues of accountability and public expectations imposed on institutions and their providers. It makes no sense for a journal to impose disclosure conditions at the end of a process that are inconsistent with terms and conditions "upstream." If the provincial governments and regional health authorities that fund the institutions in question do not require them to participate in research with a disclosure agreement, then why should they voluntarily expose themselves to the danger of "looking bad" that is inherent in comparative institutional studies. *CMAJ* merely wishing them to be "good citizens" will not make it so.