

PRO-CON

## Transparency yes, public access to outcome data no

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The call for transparency in the Netherlands is strong and increasing. Not only in healthcare but throughout society people want to know how things are accomplished and how good they are.

In earlier days doctors and healthcare institutions were trusted; nowadays, caregivers must show that they earn the trust of their patients. Caregivers must show that there is nothing to hide and that they work according to applicable standards. Most important in healthcare is to show that care is delivered with high quality. Nobody can nor wants to argue against this.

In order to improve quality and thereby outcome of healthcare treatments, we develop various quality indicators. These indicators are often collected in registers which can produce results for individual doctors, institutions and sometimes even countries. Reports on quality indicators are important incentives for medical professionals to improve and search for further improvement in the care they provide. I support all these efforts to improve medical care.

Since April 2014, hospitals in the Netherlands are obliged to publish outcome and mortality data of a series of treatments on their websites. The Netherlands Care Authority (NZA) made this obligatory in order to show in an effective, righteous, insightful and comparable way the achievements and services of the hospitals. Furthermore, the mortality figures for care by medical specialists should unambiguously and simply be made transparent, interpretable and comparable for the public. I support these highly ambitious goals, but I shall also elaborate on the restrictions I see.

In order to produce reliable (mortality) results you need a reliable source of the data you use for the analysis; the registration of the data should be flawless and interpretable without bias. In theory simple, but in practice very difficult.

Following the call for transparency, the Netherlands Intensive Care Evaluation (NICE) has decided it is time to make their data public, including mortality figures. Although I have nothing to hide and support the higher goals, at the moment I have serious

objections against publication of especially the mortality data.

The first and most important argument against the publication of the standardised mortality ratio (SMR) of the ICUs in the Netherlands is that these data will be used to compare ICUs and hospitals on the quality of care. I argue that these data are unfit for comparison on quality of care because they say nothing about quality.

Like the hospital standardised mortality ratio (HSMR) the ICU SMR is determined by multiple factors. The ICU SMR reflects not only the ICU treatment, but also the pre-ICU period and the post-ICU period in which quality of care can vary significantly, independent of the care delivered in the ICU. Furthermore, like the HSMR, besides quality of care the ICU SMR will be influenced by geographical, cultural, religious, family care factors and discharge policy.<sup>1</sup> The HSMR in the Netherlands again has been shown not to be eligible as a comparison tool for quality of care.<sup>2</sup> Moreover, it will be impossible to explain all these nuances to the public to enable unambiguous interpretation. Though I am sure the media will have no problem in doing so. But publishing these data might cause harm.

The NICE database was developed for internal feedback: how is your own performance in comparison with previous years and how is your position compared with other (blinded) ICUs with the same profile. This feedback on possible changes in performance guides you in developing strategies for further improvement. These data and improvement strategies are discussed with the Health Care Inspection (IGZ) which ensures necessary action. Within the NICE there is room for interpretation and therefore of registration of basic data. Without external pressure, besides the IGZ, there is no argument to change this registration. After publishing SMRs there will be external pressure to influence data in order to improve the numbers on this outcome. Imagine your neighbouring ICUs have better SMRs than you have, you will do everything legally and within NICE rules to change that to your advantage. One of these ways is to enhance the basic starting data and their gathering. These actions will improve

your SMR, but have nothing to do with a higher quality of care. Another way to improve your SMR is to actually change the way you treat or not treat your patients. If this change is an improvement for the patient you have my support. But it is also easy to change treatment, or withhold it, without any benefit for the patient. The patient might even be harmed. For example, withholding ICU access for groups of patients with a very high chance of dying in the hospital will improve your SMR significantly, because many who die will never enter the ICU. Your first reaction to this suggestion will be denial, but I am not so sure. Within the all accepted policy of 'do not treat all you can but treat only what is sensible', such choices might become easier, but have nothing to do with improvement of quality of care. On the other end, prolonging treatment to prevent people from dying in the hospital will also improve your SMR. An undesirable ending in nursing homes may be the downside and again the improvement of the SMR has nothing to do with higher quality. Also the availability of nursing homes or other discharge facilities will influence your SMR. I am afraid that the aforementioned perverse stimuli are not only hypothetical.

### Response to the article of Evert de Jonge

It is highly improbable that patients will make their own choice of hospital once they become critically ill or when they have critical complications from other treatments. At best, their relatives may find some information on ICU performance after their kin is admitted to an ICU. I think this will rarely lead to transport to another hospital. More likely third parties will try to use these data to 'manage' healthcare.

The treatment in ICUs is multidisciplinary and the case-mix of patients is enormous. Results of ICU treatment is also determined by pre- and post-ICU care. Mortality of ICU treatment is seriously influenced by geographical, cultural, religious and family care factors and also by discharge policy and possibilities. Although most popular in medical literature, I

Therefore I can only conclude that we have no reliable unambiguous data on quality of care in the ICUs in the Netherlands. The available SMRs are a second best. Publishing these data will lead to unfair comparison and might have harmful side effects. These data may be unfairly used by politicians and Health Insurance Companies to restrict ICU care in hospitals on the basis of hypothesised quality. I am against publishing these data because it will not contribute useful information. We must not give in to the call for transparency and provide the public with uninterpretable data. Instead, I suggest we develop other outcome parameters to better describe quality of care in the ICU.

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### References

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2. Kievit J, Tamsma J, Marang-van de Mheen P. HSMR ongeschikt voor ziekenhuisvergelijkingen. *Medisch Contact*. 2014;38:1820-2.

doubt that mortality figures only will ever determine quality of care in the ICU. Of course we must take changes in SMR into account on improving quality strategies but it should not be considered the single best quality parameter.

A new development is patient reported outcome measures (PROMS). Quality of life after ICU admission is already an important subject of investigations. But there should be more and better ways to get specific feedback from patients that will direct us to further improvements. Also family reported outcome measures (FROMS) are a new dimension in getting feedback on our efforts in the ICU. Instead of showing second best data to the public, we should start looking for and improving our outcome parameters.