

Improving quality of care for rare congenital malformations

Achieving standardized quality measurement and improvement through international clinical auditing

1. Standardization of collected parameters and measurement instruments and centralization of data collection are especially valuable in rare conditions. (*This thesis*)
2. Core outcomes defined for standardizing parameters studied and reported in research are not necessarily good indicators to evaluate quality of care. (*This thesis*)
3. Fair benchmarking aimed at quality improvement requires data from all treated patients and is inherently biased when requiring informed consent. (*This thesis*)
4. The *European Pediatric Surgical Audit* is an effective care measurement tool to identify clinical practice variation, even when applied on a small scale. (*This thesis*)
5. The mere existence of *European Reference Networks*, such as the *European Reference Network for Inherited and Congenital Anomalies*, is an instigator for enhancing quality of care for rare conditions in Europe. (*This thesis*)
6. To be recognized as an expert center for the treatment of any condition, standardized data collection for quality improvement purposes should be a prerequisite.
7. It is one of the essential features of incompetence that the person so inflicted is incapable of knowing that they are incompetent. To have such knowledge would already be to remedy a good portion of the offense. (Miller, 1993; as referenced by Kruger and Dunning, 1999)
8. Open-access publishing of peer-reviewed scientific papers should be the norm, with no imposition of fees whatsoever.
9. Pursuing a PhD is like running a marathon. It requires consistency, discipline, and, above all, the ability to celebrate small victories along the way.
10. Het poneren van een aantal stellingen als bijlage bij een proefschrift, met als oorspronkelijke intentie het aantonen van kennis en/of interesse in meer zaken dan alleen het onderwerp van het proefschrift, is dit doel volkomen voorbijgeschoten. (Wim Teunissen, 2 juni 1988)
Posing multiple propositions as an appendix to a PhD thesis, initially aimed at showcasing the author's broad expertise and interests beyond the thesis subject, has entirely exceeded its original objective. (Wim Teunissen, June 2 1988).
11. De meeste mensen deugen. (Rutger Bregman, 2019)
Humankind: a hopeful history (Rutger Bregman, 2019)