Extreme Prematurity Care

Reasonable Progress or Therapeutic Fury*?

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***accanimento terapeutico**

I have no financial relationship with manufacturers of any product nor any professional conflicts-of-interests to disclose.

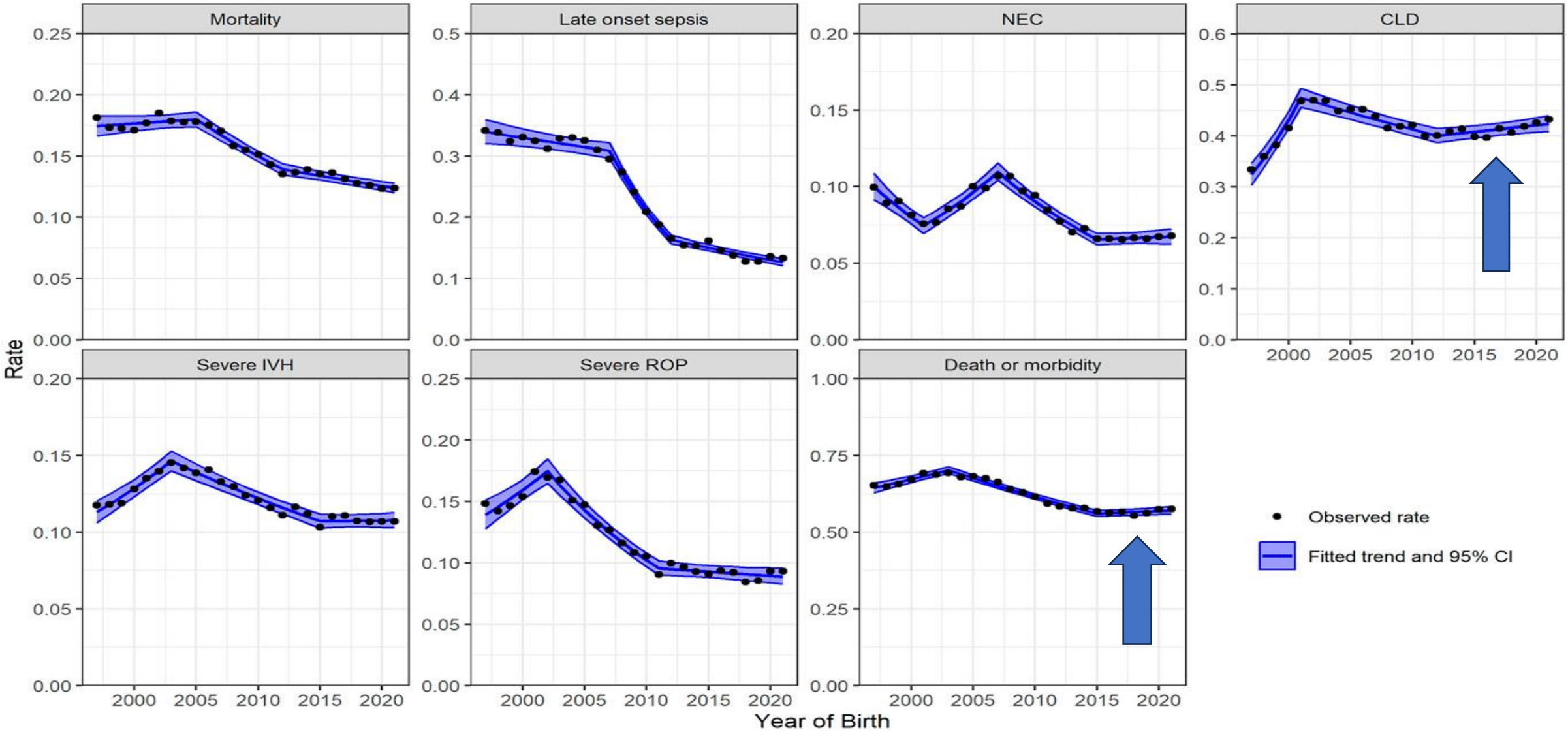
I claim no special moral authority simply because I am a physician.

The primary virtue of Man is to understand.
Everything excellent is as difficult as it is rare.

Baruch Spinoza 1632-1677

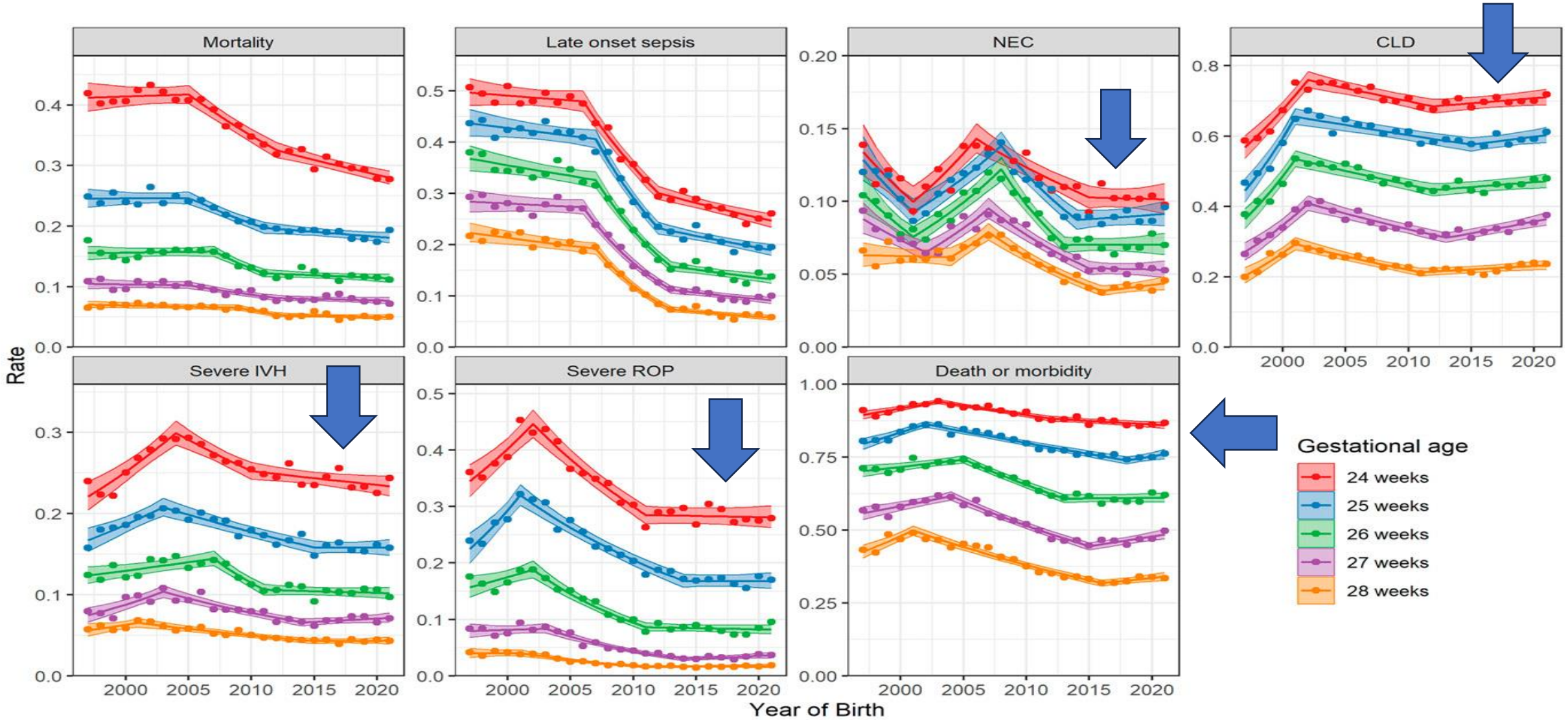
My sole goal is to connect good reasoning to goodness.

Philippa Foot 1920-2010



Previous VON improvements in mortality and morbidity in 24–28-week infants have slowed, stalled, or reversed. How? Why the ~2010-12 change?

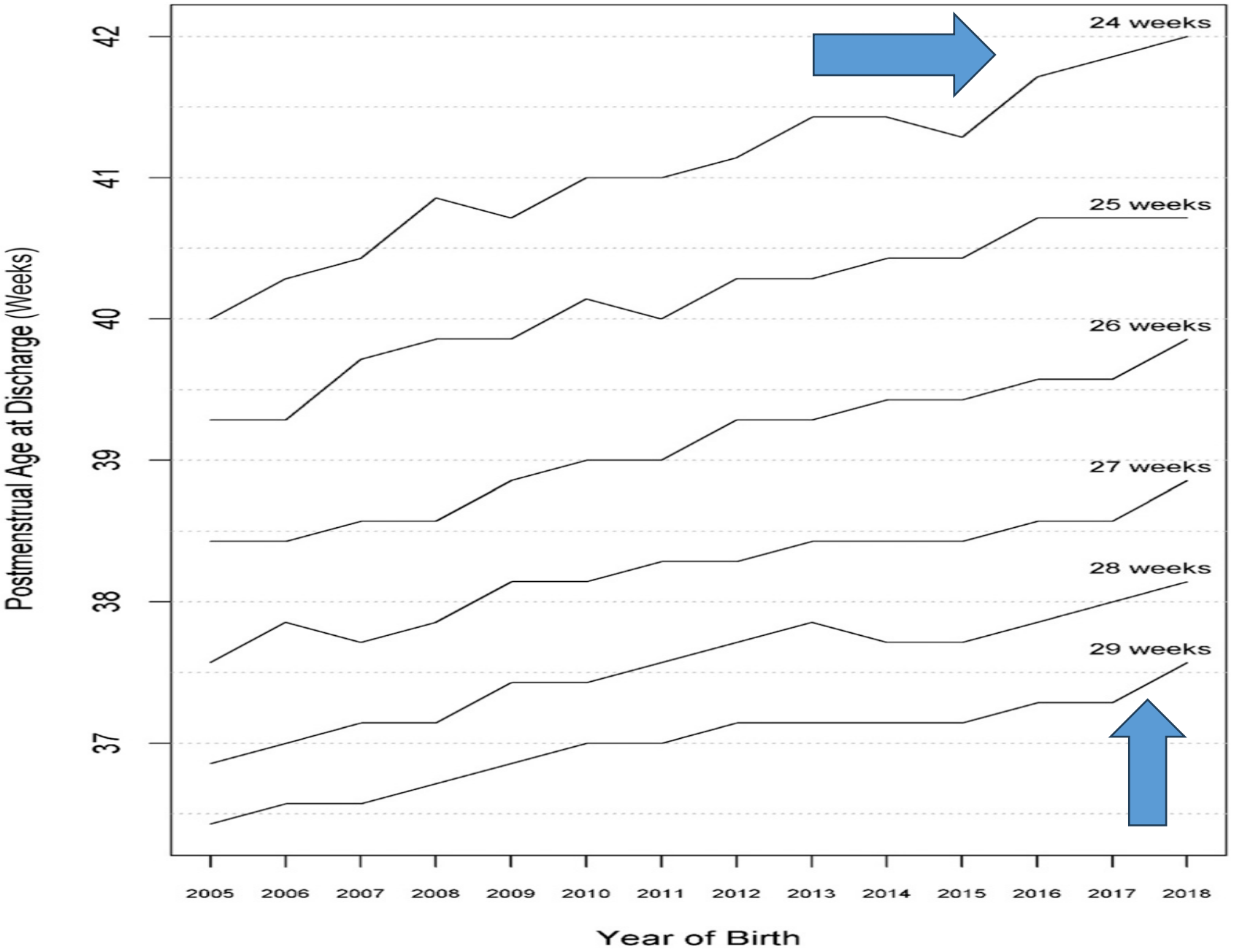
Horbar et al, *Pediatrics* 2023.



24 and 25 week infants have especially concerning morbidity trends.

How? Why the ~2010-2012 change?

Horbar et al, *Pediatrics* 2023.

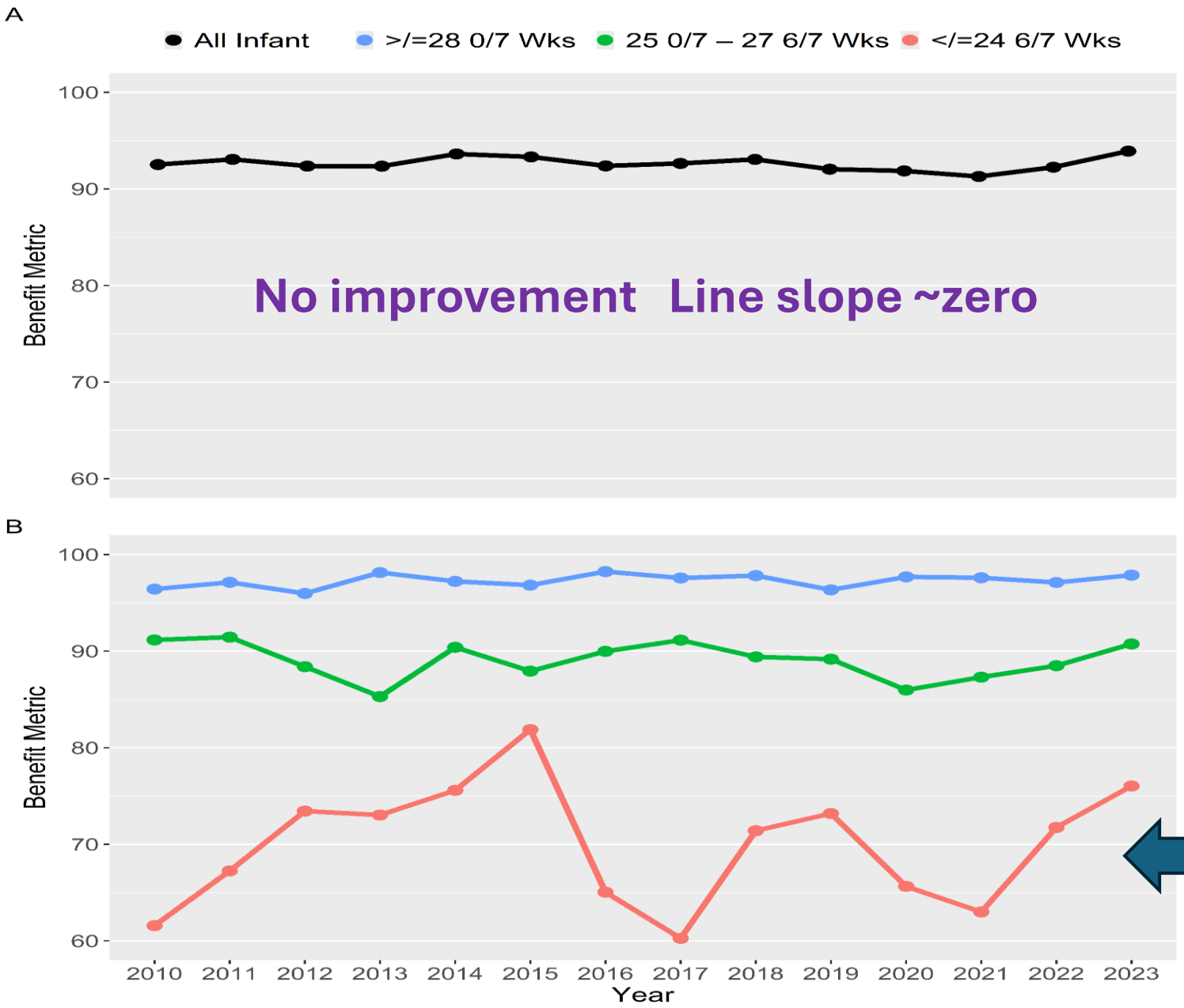


24-29 week length-of-stay is significantly increasing.

Why?
How?

Edwards et al, *Pediatrics* 2021.

So, our "product" we are selling from our "factories" is NOT improving, yet is MORE expensive…



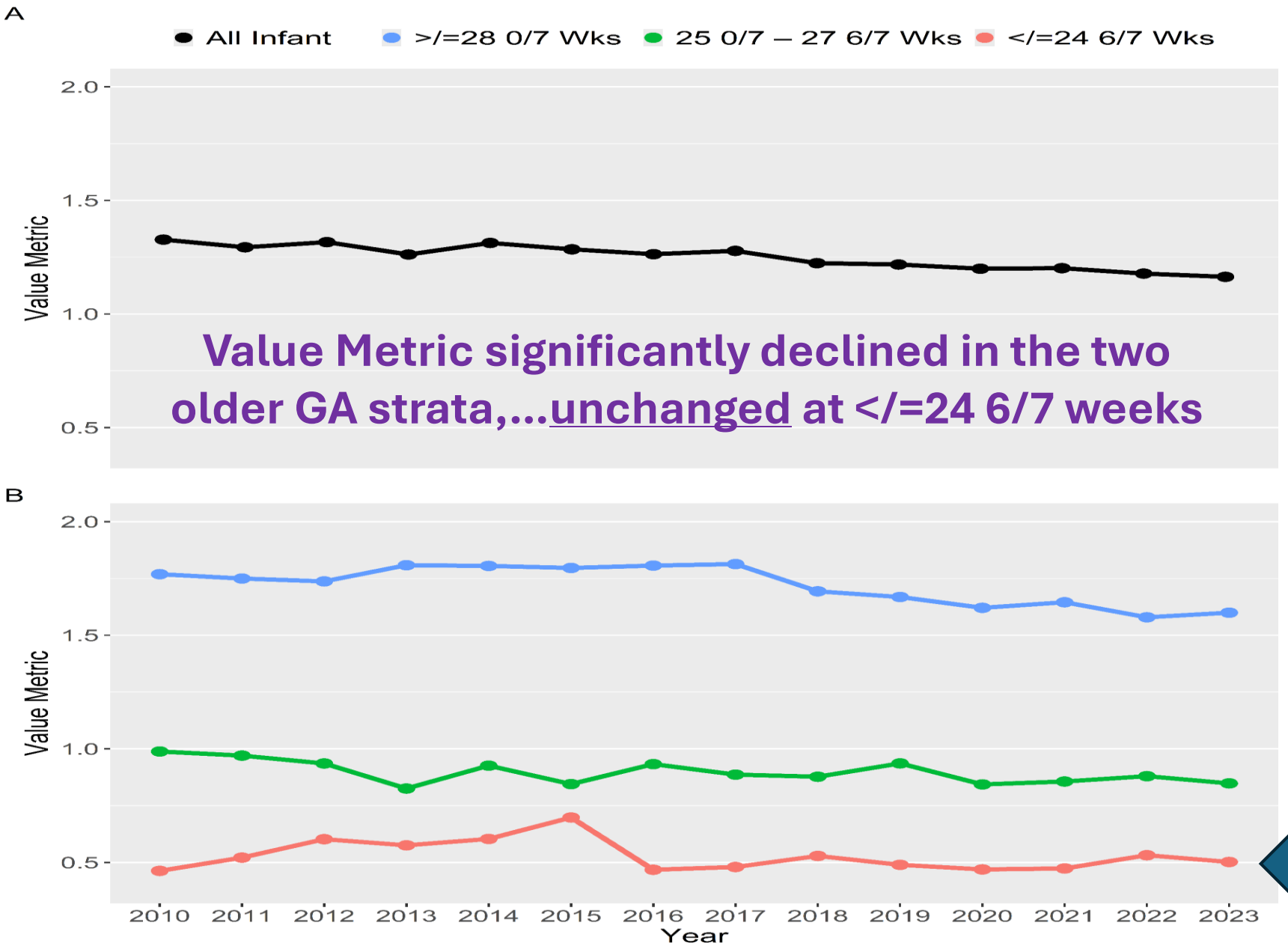
Benefit Metric

VLBW 7 Major Morbidities Composite, risk-adjusted score

CLD SIVH SROP
PVL NEC FIP
Any Late Infxn
Mortality Deduction

How proficient is a NICU in minimizing death and/or the 7 major morbidities?
Higher score = Less death and/or morbidities

16 PSJH NICUs
2010-2023
N = 11,795



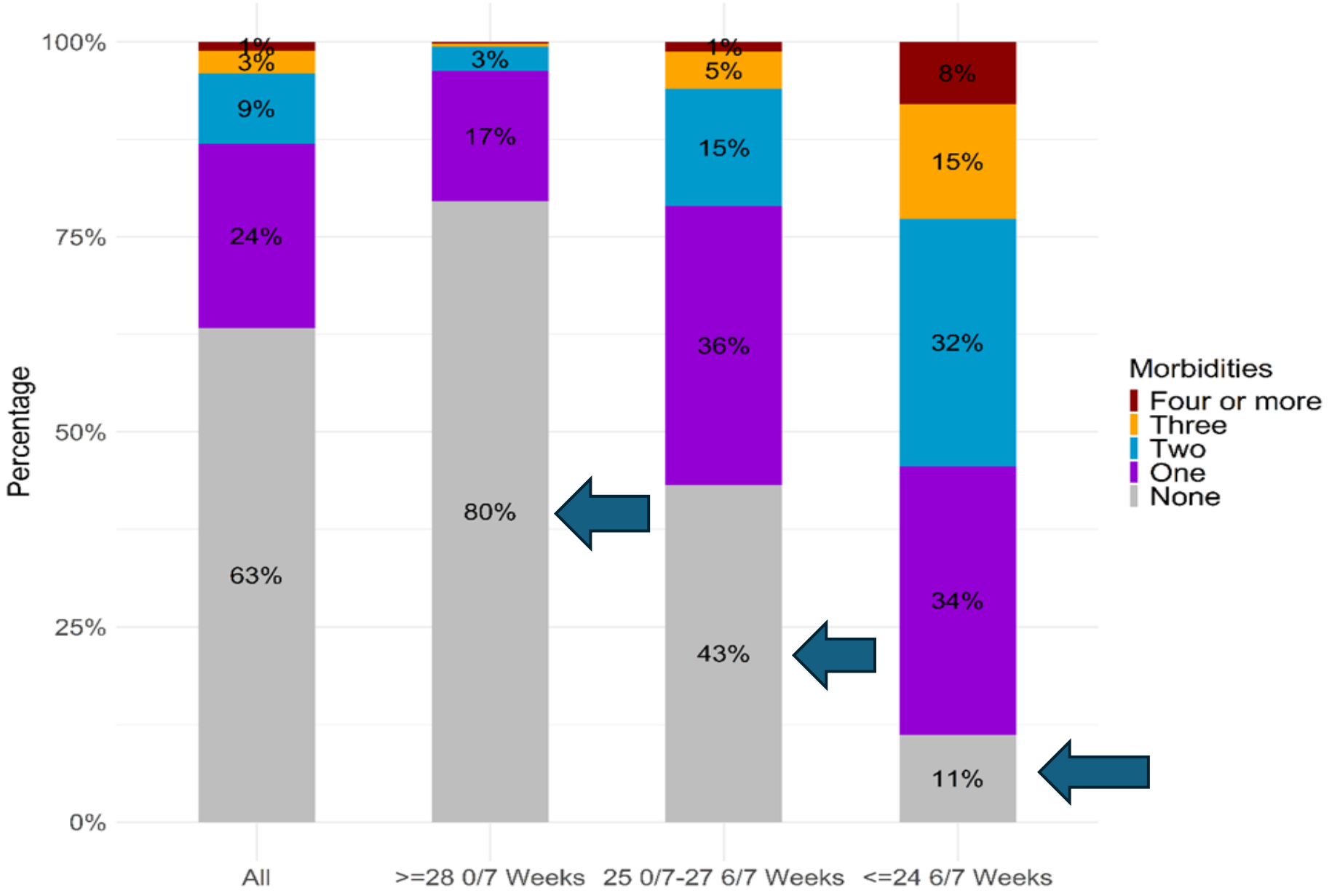
Value Metric

Benefit Metric normalized to the Total Hospital Length of Stay in Survivors

THLOS = Cost-proxy

How efficient is a NICU in VLBW infant quality improvement?

Higher score = More favorable benefit/cost ratio.



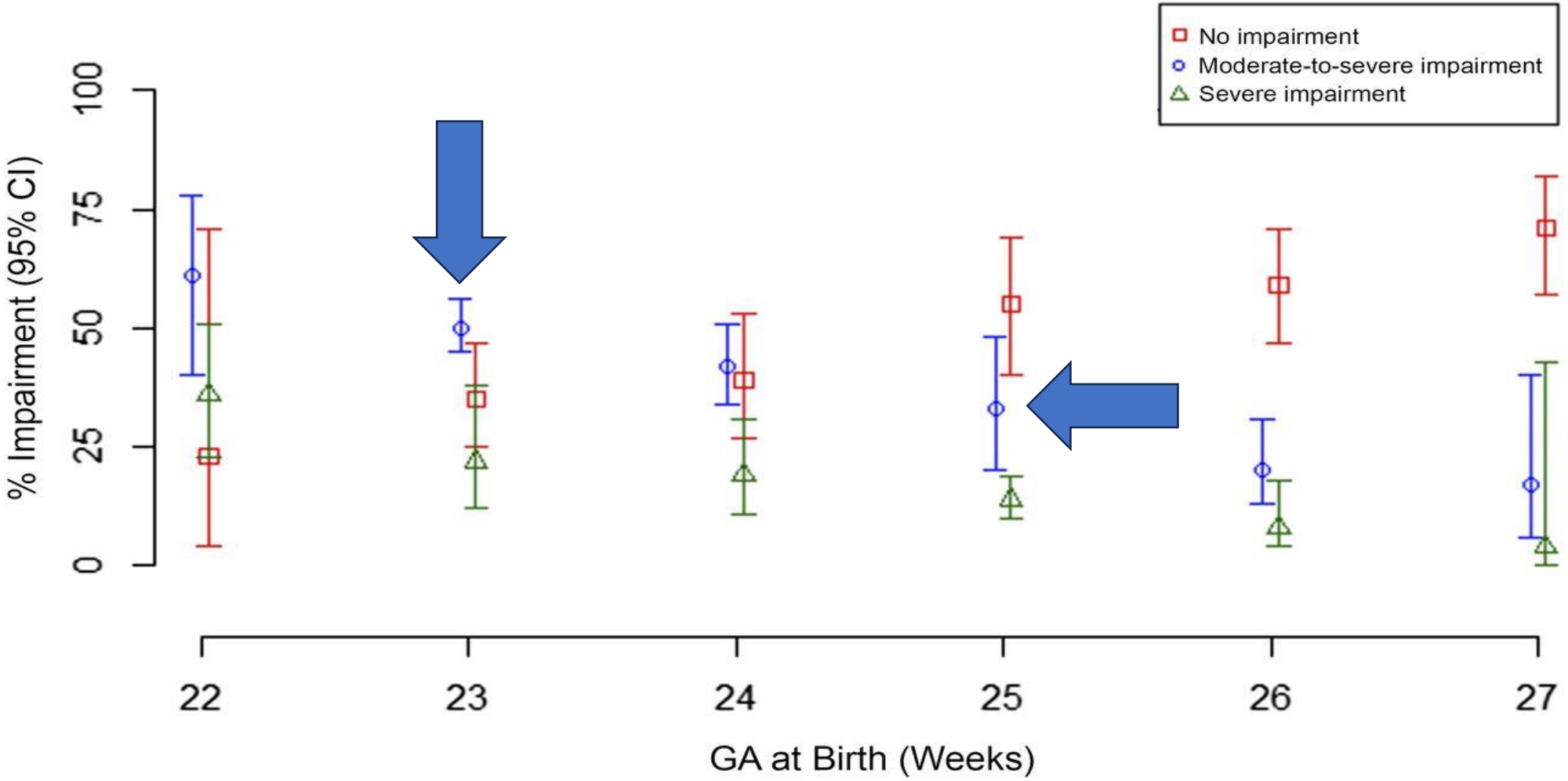
Providence St. Joseph Health System QI Collaboration
16 NICUs 2010-2023
10,670 Surviving VLBWs

The gray area in the bars next to arrows: 0/7 major morbidities

This is approximately the same percentage of "Normal Neurologic Development" in diverse follow-up studies.

That is amazing!

Neurodevelopmental outcomes for premature infants born <28 weeks GA



Myrhaug et al, *Pediatrics* 2019

Are neurodevelopmental impairment rates for infants born 22 to 26 weeks' gestation changing over time comparing time-separated cohorts from a given NICU or study group?

Survival rates have increased, but have neurologic outcomes improved?

Joseph Kaempf, MD, MSc
Úrsula Guillén, MD
Jonathan Litt, MD, ScD
John Zupancic, MD, ScD
Haresh Kirpalani, MD, MSc

Meta-analysis studies needed to report:

1. Infants born 22-26 completed weeks' gestational age or <1000 grams birth weight,

2. From at least 2 discrete cohorts,

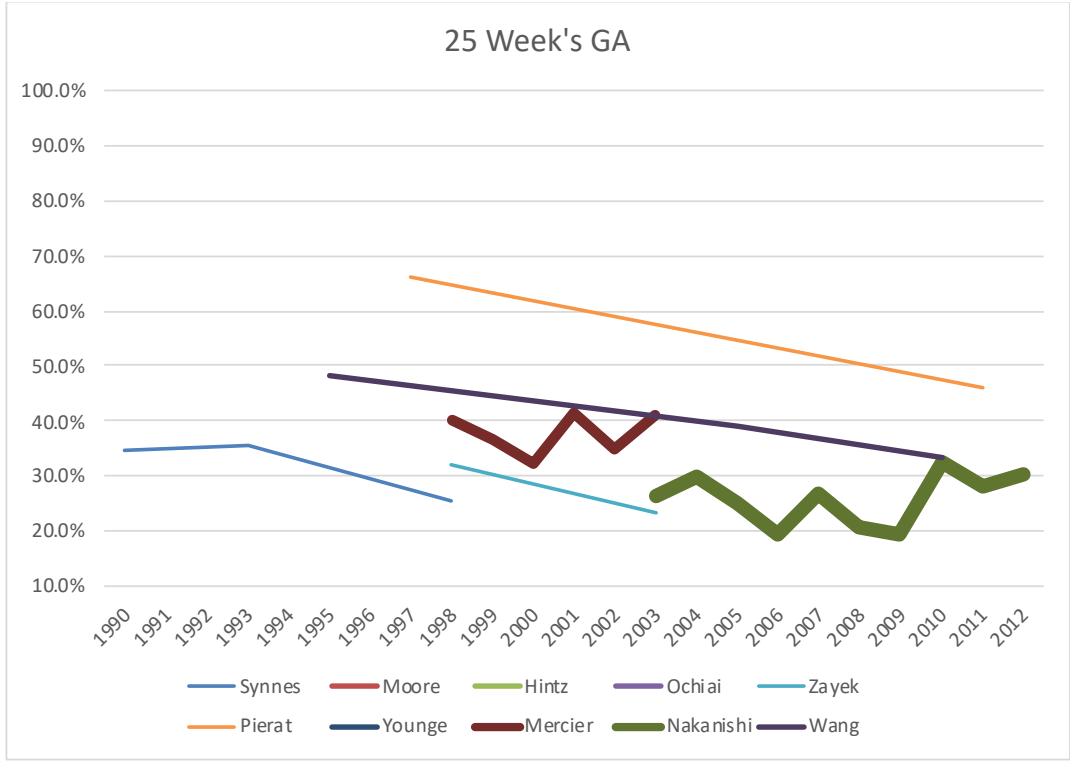
3. Cared for within the same NICU or study group,

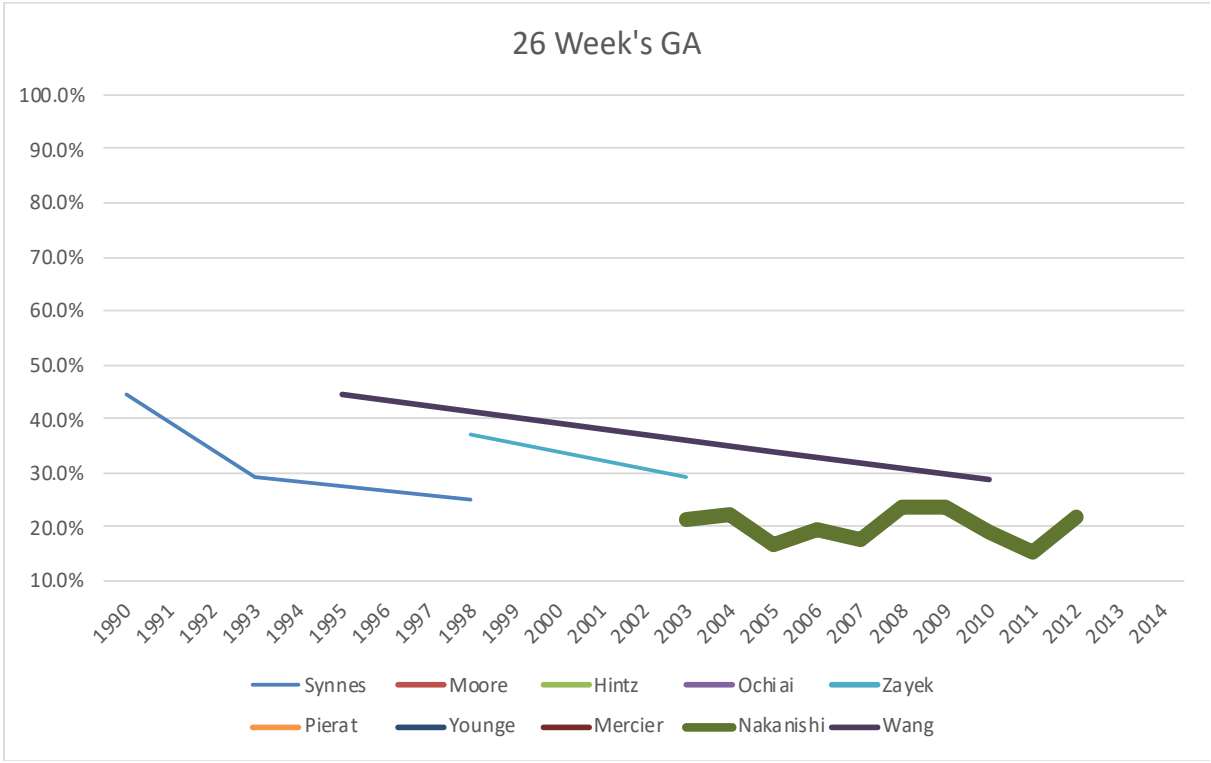
4. One cohort born 1990 or after, compared to one or more distinct cohort(s) born later.

Kaempf, Guillen, Litt, Zupancic, Kirpalani *Arch Dis Child FNN*, 2022

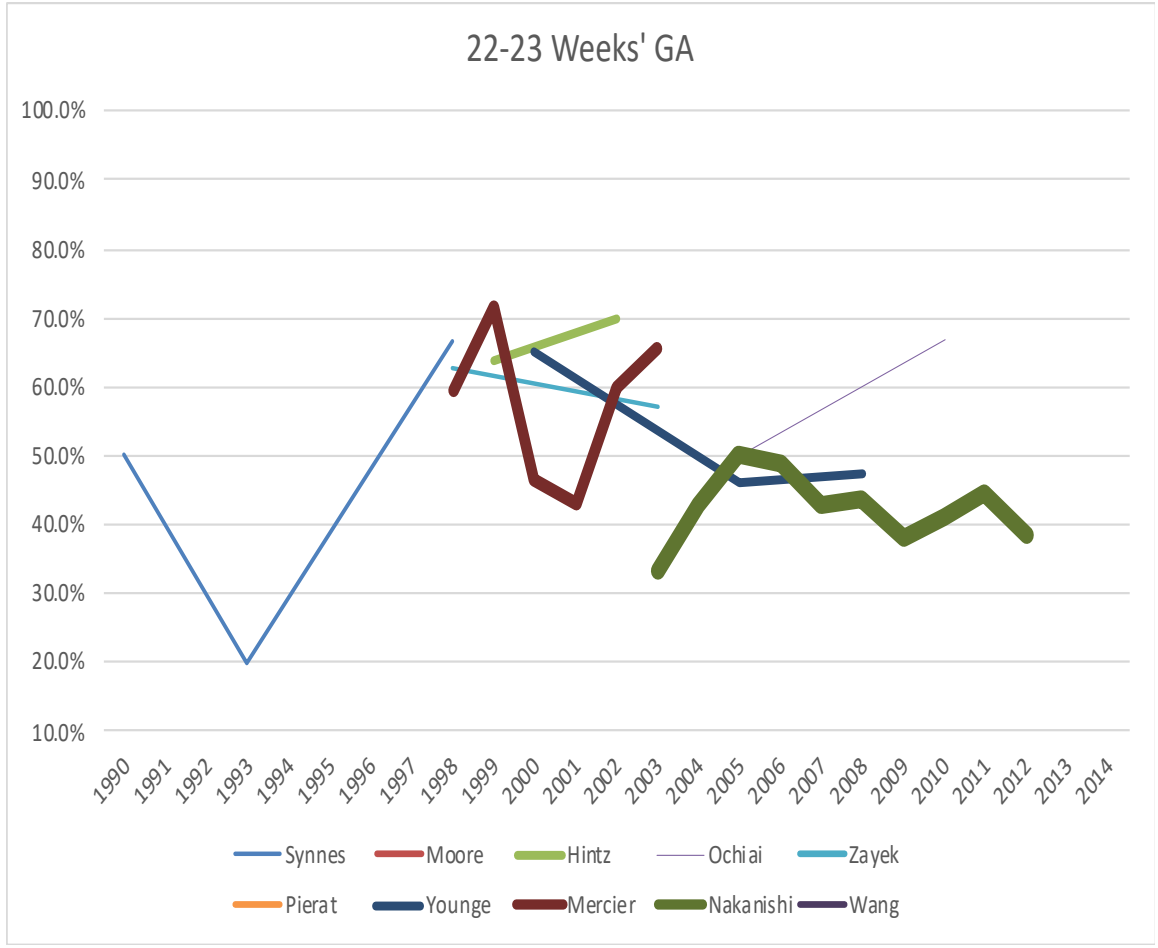
Some evidence of improving neurologic outcomes at 25-26 weeks.

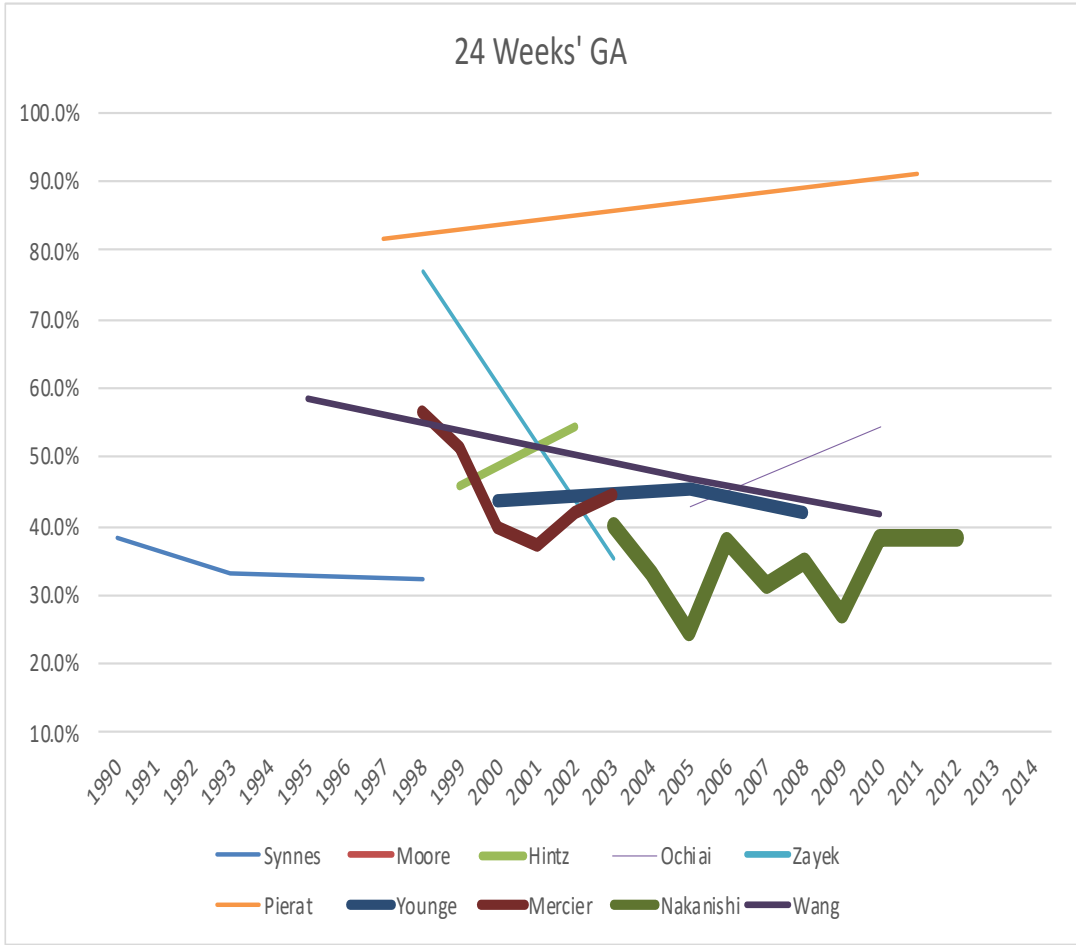
It is not until 26 weeks that infants have a >50% chance of surviving with no neurologic impairment.





Kaempf, Guillen, Litt, Zupancic, Kirpalani *Arch Dis Child FNN*, 2022





No evidence of improving neurodevelopmental outcomes at 22-23-24 weeks.

Chance of surviving with no neurologic impairment <20%.

Resuscitation rates are increasing at 22-23-24 weeks

Survival rates are increasing at 22-23-24 weeks

Long term comprehensive neurologic outcomes are not improving at 22-23-24 weeks

High resuscitation rates at 22 and 23 weeks do not translate to the most favorable major morbidity rates at 22 to 27 weeks.

Compare NICHD Neonatal Network reports to the VON 'POD', EPIPAGE, and Swiss Neonatal Network reports.

Kaempf JW, et al, *ADC FNN* 2020

Vermont Oxford Network 2023 Resuscitation Rates

	Resuscitated	Survival
22 Weeks	75%	24% (0, 46)
23 Weeks	93%	48% (0, 73)
24 Weeks	98%	64% (40, 100)

Of all tyrannies, a tyranny exercised for the good of its victims may be the most oppressive…those who torment us for our own good will torment us without end, for they do so with the approval of their own conscience.

C.S. Lewis

Random Sample in 2023 VON

100 infants Born @23 Weeks

93 are resuscitated

45/93 survive to discharge

23/45 have significant brain injury and NDI

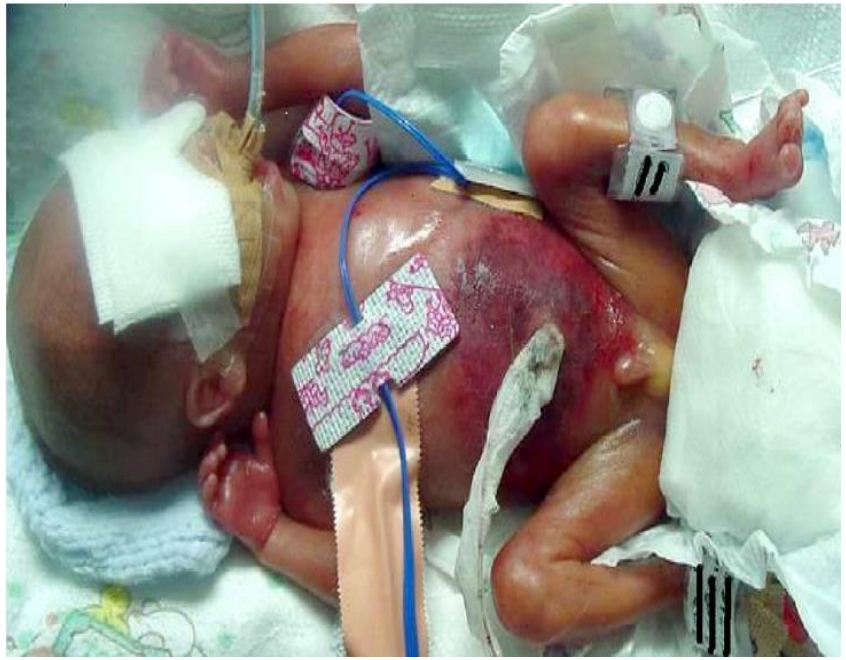
17/22 w/o NDI have neuropsychiatric impairments, autism, ADHD, special school needs, behavioral and/or executive function disorders.

Just 5 of the original 93 resuscitated infants experience full neurodevelopmental and psychologic health.

If we are victorious in one more battle with the Romans, we are ruined.

King Pyrrhus of Epirus
Battle of Heraclea, 279 BCE

We agree – There is a boundary at which a premature infant's neurologic impairments can be so significant that a family might prefer palliative comfort care.



We agree – It's uncertain whether 22-23-24 week NICU care will result in a healthy child, or a child with neurologic impairments and chronic health issues.

We agree – Physicians, families, ethicists, society have **never** been able to determine an acceptable or fair ratio between the likelihood of the above two uncertainties.

Sorites Paradox

"The Line of Demarcation"

What is a heap of sand?

When exactly is it dark?

If we cannot precisely define even the most concrete events, how can we define "quality of life",….or "suffering",….or "neurodevelopmental impairment"?

If we cannot concisely define a situation with clarity, accuracy, and fairness,…..then perhaps we ought not take inflexible positions.

There is no USA state or federal law which mandates resuscitation of extremely premature infants. Both "*wrongful death*" and "*wrongful life*" lawsuits have been litigated.

Baby Doe Laws

CAPTA

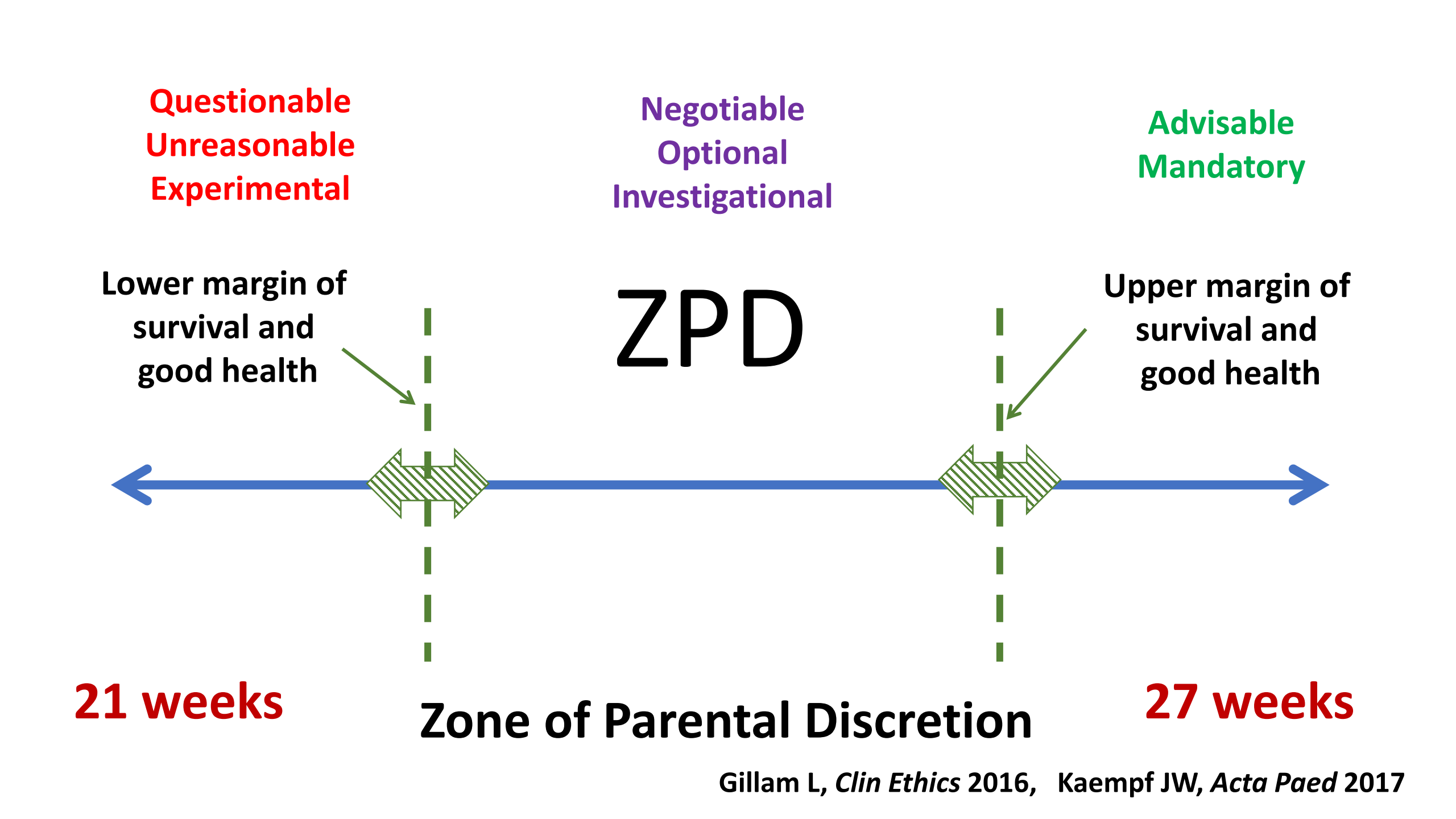
EMTALA

BAIPA

Executive Order 13952 (2020)

The definition of alternatives in any dispute is the supreme instrument of power; whoever determines the options runs the country.

E.E. Schattschneider
1960



Gillam L, *Clin Ethics* 2016, Kaempf JW, *Acta Paed* 2017

<u>Uncertainty</u> means you are not sure what will happen. This, physicians understand.

<u>Risk</u> is the product of: a) something harmful happening and, b) the probability it will happen. This, families understand.

Is it permissible (or relevant) for a physician to mention that she/he is the parent of a premature infant?
Does that confer special moral authority?

Should every obstetrician be a woman?
Every urologist a man?
Are the best oncologists those who have had cancer?

Is it problematic for a neonatologist to promote NICU care for extremely premature infants while his income is high six-figures and with a bonus structure related to census?

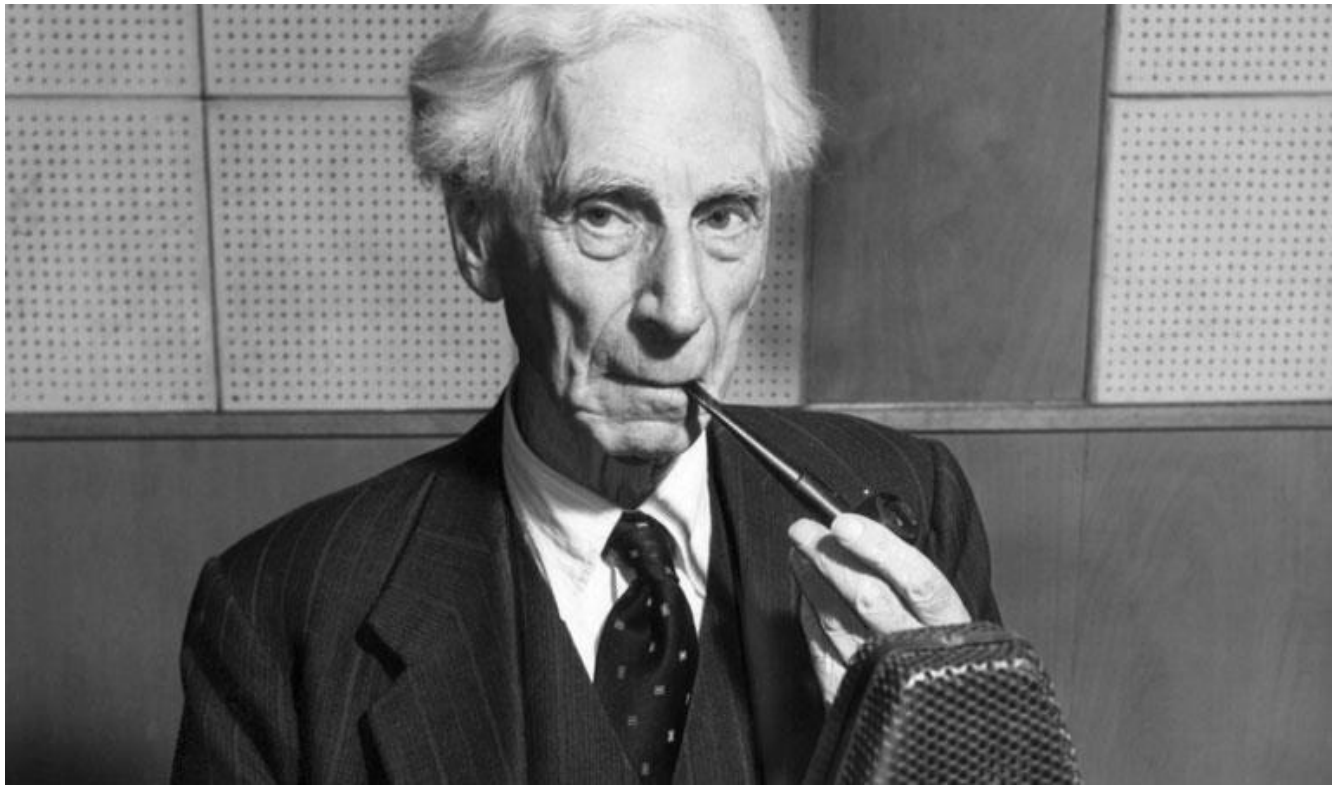
Is it a conflict-of-interest for a neonatologist to advocate NICU care for extremely premature infants while her principal research interests are CLD and brain injury?

Might a physician who recommends comfort care not be particularly skilled, or burned out, and/or on a fixed salary regardless of NICU census?

How do we mediate a clash of "*moral values*" amongst a pregnant woman at 23 weeks, an obstetrician, a nurse, a neonatologist, a hospital administrator, and a family member?

….a Protestant, a Jew, a Buddhist, a non-theist, a Catholic, and a Unitarian,….one had a healthy premature infant, one a handicapped child, and one no children.

Any desire, if strong enough, will produce its' own morality.



Bertrand Russell

1872-1970

What do women think years after the birth of their 22-25 week infant?

Decision Regret - "Active Care" v. "Comfort Care" v. "Other"

2004-2019 787 eligible women 2 health systems

242/787 (31%) completed survey

Regret scores elevated in all 3 groups, highest in "comfort care"

Less regret significantly correlated with:

1. **Prenatal consult done with OB/Neo**
2. **Woman indicated she was the primary decision-maker, not the MDs**
3. **Child alive at the time of survey***

***highest scores (100) in two women with NDI children**

Belden, Kaempf, Guillen et al, ***Arch Dis Child FNN*** 2024

10% of USA's ~3.7 million births/year are <37 weeks.

22 to 25 weeks births are

~0.3% of USA births – **12,000/year**

USA will spend $4.4 trillion in 2025 on healthcare.

~2% is newborn care first year of life - **$90** billion/year

Extremely premature infant survivor costs first year of life

~$750,000 - $1,500,000.

Does **not** include $$$ NICU deaths, out-of-pocket expenses, lost opportunity costs, employment restrictions, expenditures after year one, nor sibling effects.

USA 2024 fertility rate 1.63

Opportunities to improve short and long-term outcomes of 22-25 week infants?

Antenatal corticosteroids 6 hours - 7days before birth

MgSO4

Placental Transfusion

Euthermia

NCPAP/NIV as feasible

Early surfactant - LISA/MIST as feasible

Minimize mechanical ventilation

Colostrum/Breast milk/Early feeding protocols

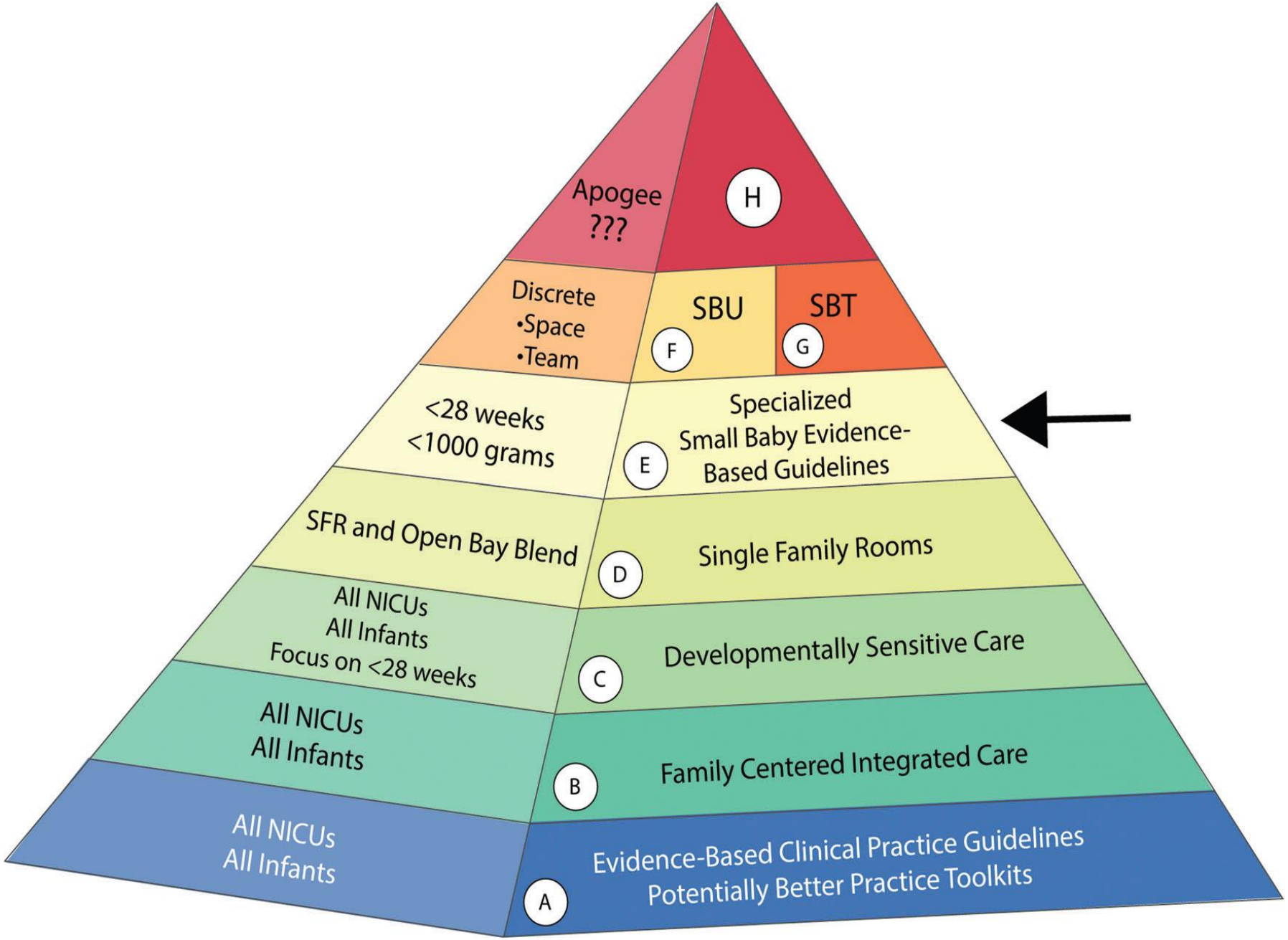
Probiotics

Minimize kinesthetic/light/sound stress

Kangaroo care

Reduce painful procedures/blood draws

Minimize antibiotics



Small Baby Units

Popular
Expensive $$$
Marketing Tool…?

SBUs have <u>not</u> reliably improved mortality, morbidity rates, nor neurodevelopmental outcomes.

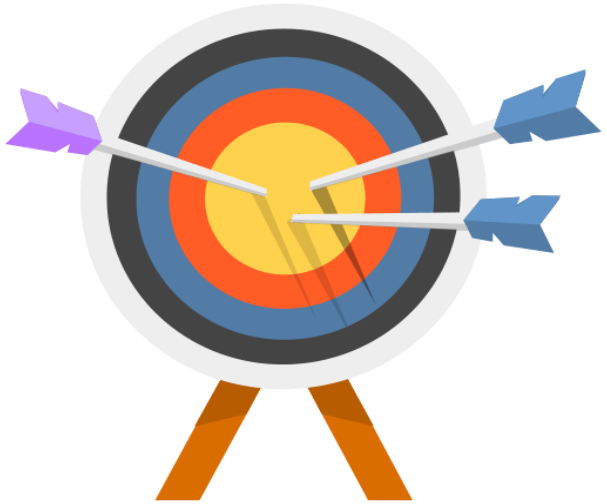
Kaempf and Gautham,
***J Perinatology* 2021**

King Pyrrhus update

It is an axiom that action for short-term human benefit will bring long-term ecological or social problems which will demand unacceptable effort and expense for their solution.

Nobel Prize Laureate, 1960

F.M. Burnet



The Triple Aim

Improve Population Health

Improve Individual Care Experience
STEEEP

Improve Affordability Reduce Cost

Is this a realistic aim?

75% of diagnostics and therapeutics in healthcare do NOT have a solid evidence base.

"That's just how we do it here."

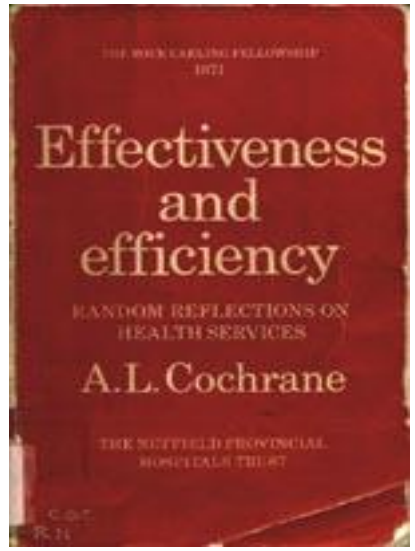
John Ioannidis

***Why Most Published Research Findings are False, PLoS Med*, 2005**

EBM Triple Aim

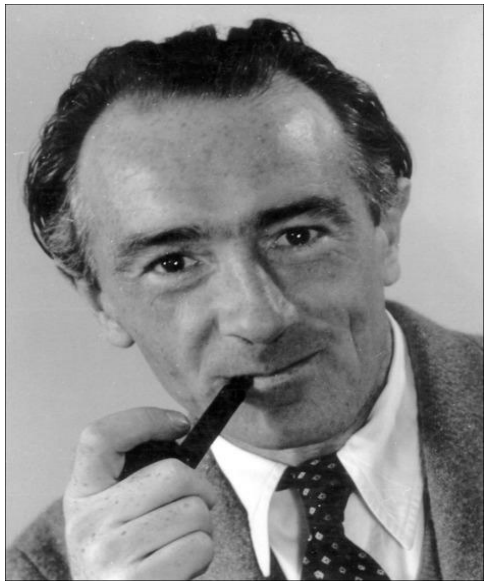
Population Health and Patient Preference

Value Pluralism



Best Available Evidence

RCTs
Meta-analyses
Systematic Reviews
Observational ITS Trials
Artificial Intelligence LLMs
EHR Clinical Decision Tools



Clinical Expertise

Big Picture Wisdom
Knowledge and Experience
Group Culture Awareness
Reason/Compassion/Responsible

THE FUNDAMENTAL ISSUE

How do we decide if the rights and "best interests" of pregnant women and family are in agreement or conflict with the "best interests" of the fetus/infant?

How is the infant's "best interest" brain injury, chronic health issues,…or death?

Are pregnant women obligated to agree to comfort care or NICU care because (through no intention of their own) they might deliver an extremely premature infant?

The fundamental issue is NOT:

a) can these infants survive

b) can they be healthy

c) can they rate their lives as good

d) do we have the resources to care for premies

e) we provide extraordinary measures of ICU care for sick children and adults

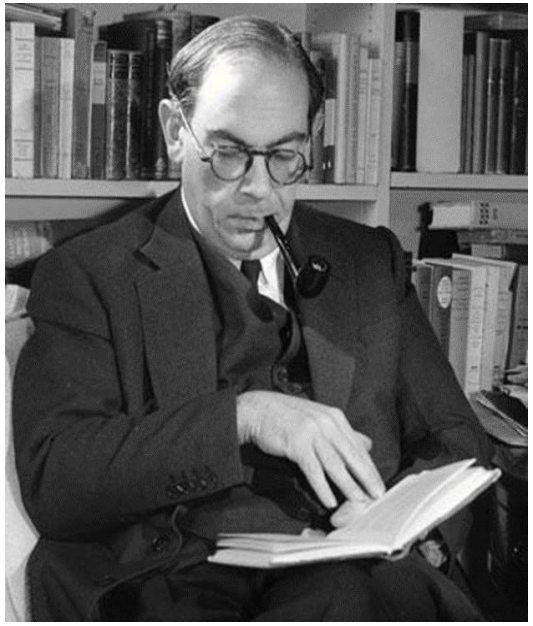
Just my opinion:

The essence of periviability dialogue is not to establish moral truth, nor to negotiate "best interests", nor to character-build.

Our authentic purpose is to clarify the meaning of extremely premature birth to the pregnant woman,….and obtain informed consent.

Value Pluralism

Human values are irreducibly diverse, often conflicting, and ultimately incommensurable.



Isaiah Berlin

Fundamental tenets of right and wrong are context dependent and hugely arguable.

Choices often must be made in which every available option involves some degree of loss or pain.

Take Home Thoughts

Formulate consensus periviability dialogue guidelines and use decision aids.

Do this at your hospital via broad consensus; be inclusive of diverse sentiments, aka value pluralism.

Read deeply – others' guidelines, long-term outcomes, woman and family viewpoints, history, philosophy, economics, novels, poetry….

Have you ever met a woman who delivered an infant <25 weeks who believes that mandatory comfort care or NICU care should be a hospital or societal policy…?

Have you ever met a female obstetrician who believes pregnant women should be required to have 22-23-24 week infants resuscitated…?

Moralizers have all the answers….
Moralists have all the questions….

The goal of Artificial Intelligence is for health care practitioners to make as few decisions as possible,….
and for patients, families, and communities to make as many decisions as feasible.

Someday, hierarchy-based extreme prematurity directives will be replaced by AI-augmented shared decision-making.

Tragedy isn't always "*right versus wrong*".
History has never shown sustained harmony.

Reasonable progress or "*accanimento terapeutico*"…?

Tragedy is physicians, families, society refusing to acknowledge biologic and social circumstances that neither effort, intelligence, nor courage can remedy.

Might we have the forbearance and tranquility to accept that which we cannot change.
Might we have the courage to change that which we must.
Might we have the collective wisdom to understand the difference.

It's harmful and expensive to employ unproven preventives, diagnostics, and/or therapeutics.

In the long run, we do not save time, $$$, nor heartache by persisting with suboptimal, unproven, unsafe practices.

Which of us would personally choose care at a hospital mired in "average", tacitly OK with 50th percentile metrics?

The wellbeing of pregnant women and families is the foundation of every civilized society.

Contact me anytime with questions, ideas, feedback, collaboration.

joseph.kaempf@providence.org

Thank you for the greatest generosity, ….your attention.