

End-of-life decisions in neonates: a comprehensive overview of estimates, views and experiences based on three recently finished studies

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The neonatal end-of-life decisions project

Death certificate study on a population level

- ALL deceased infants aged 0-1
- Over a period of 16 months in Flanders and Brussels (Flemish mother)

Attitude study in neonatology



63% (52/83) of all NICU physicians



46% (250/527) of all NICU nurses

Interviewstudy



15 neonatologists

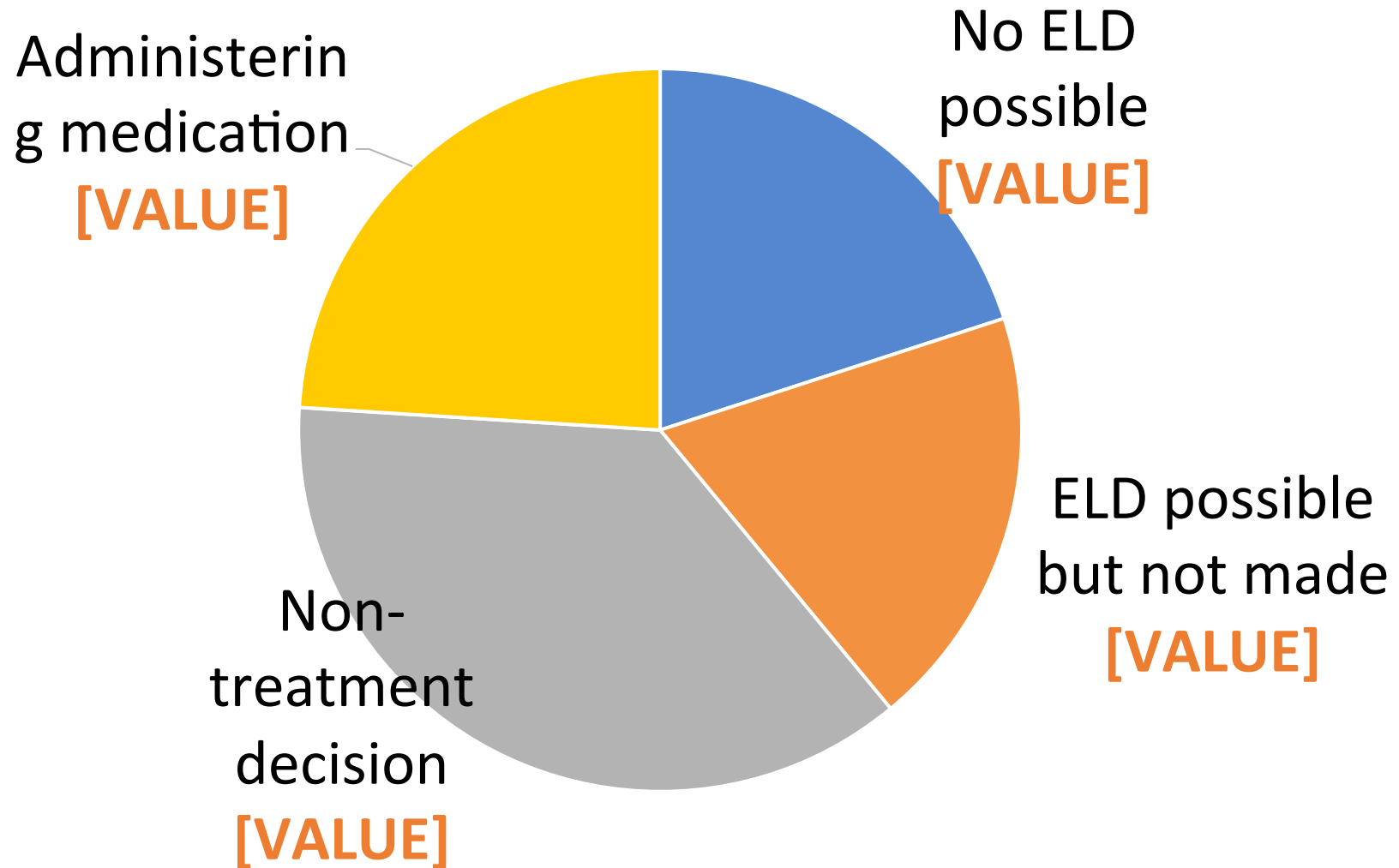


15 neonatal nurses



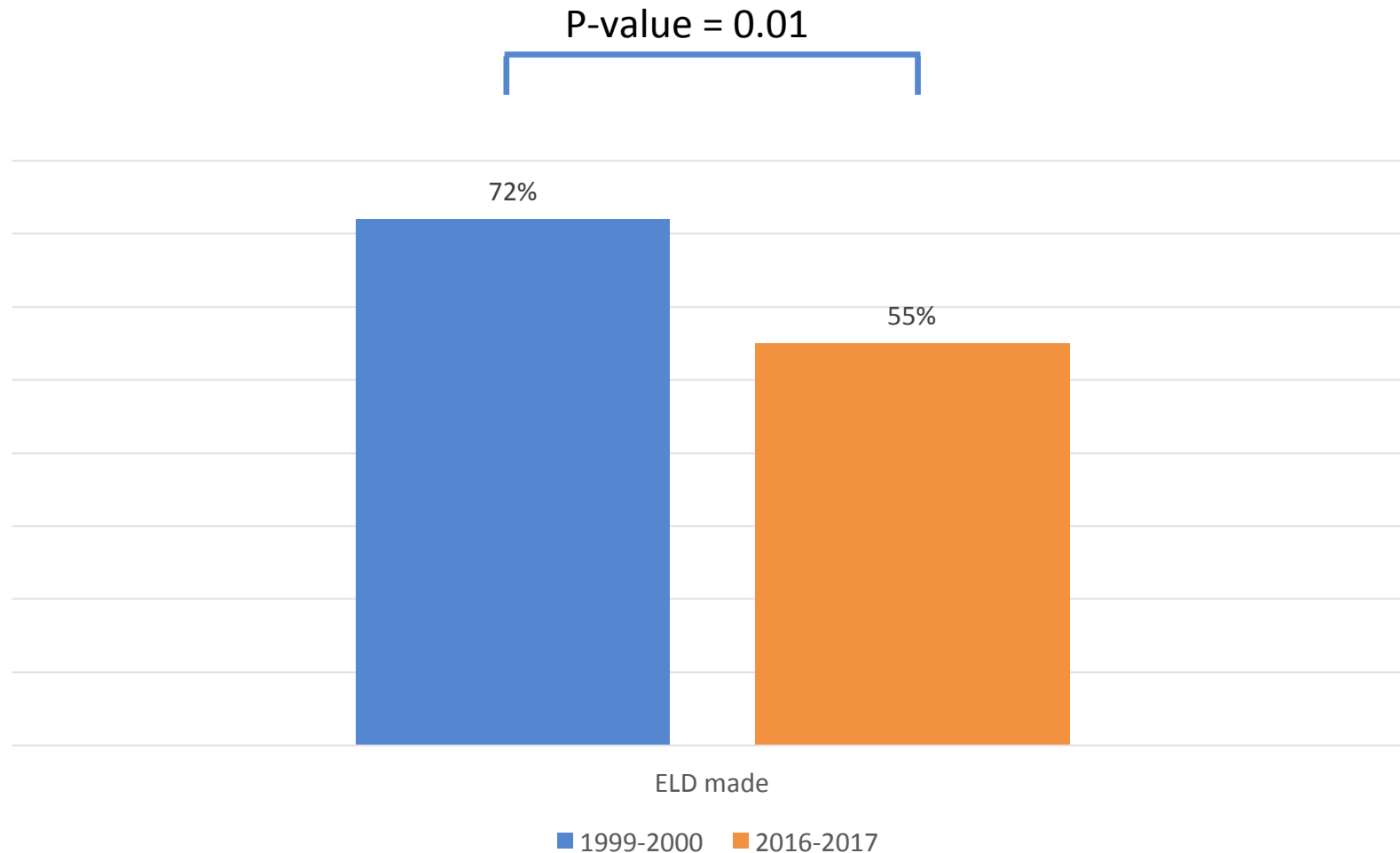
23 parents of 14 infants

Main results: **end-of-life decisions happen in 3/5 deaths before the age of one**



Significant shifts in prevalence depending on age of the infant

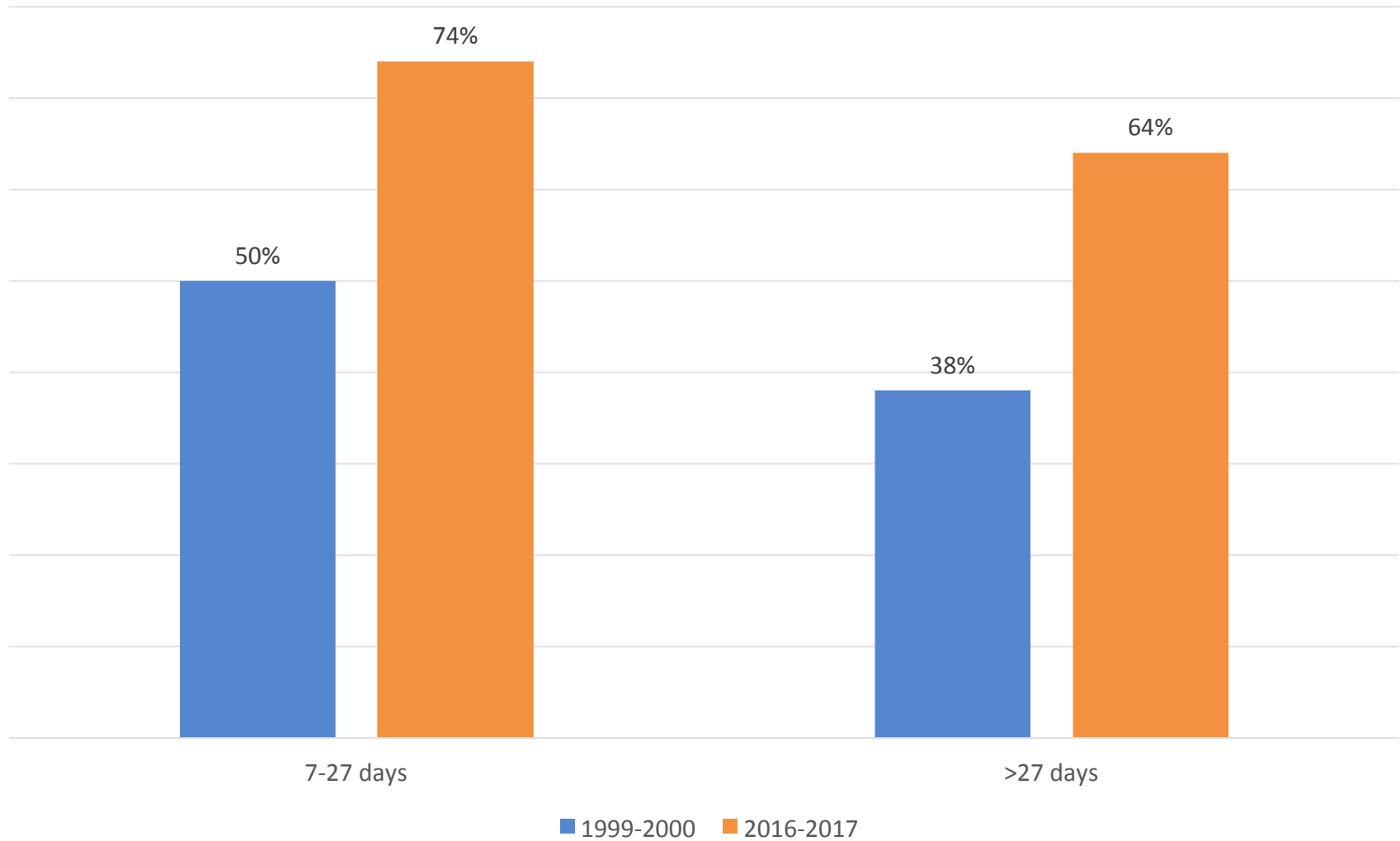
< 7 days old → decrease in prevalence of ELDs



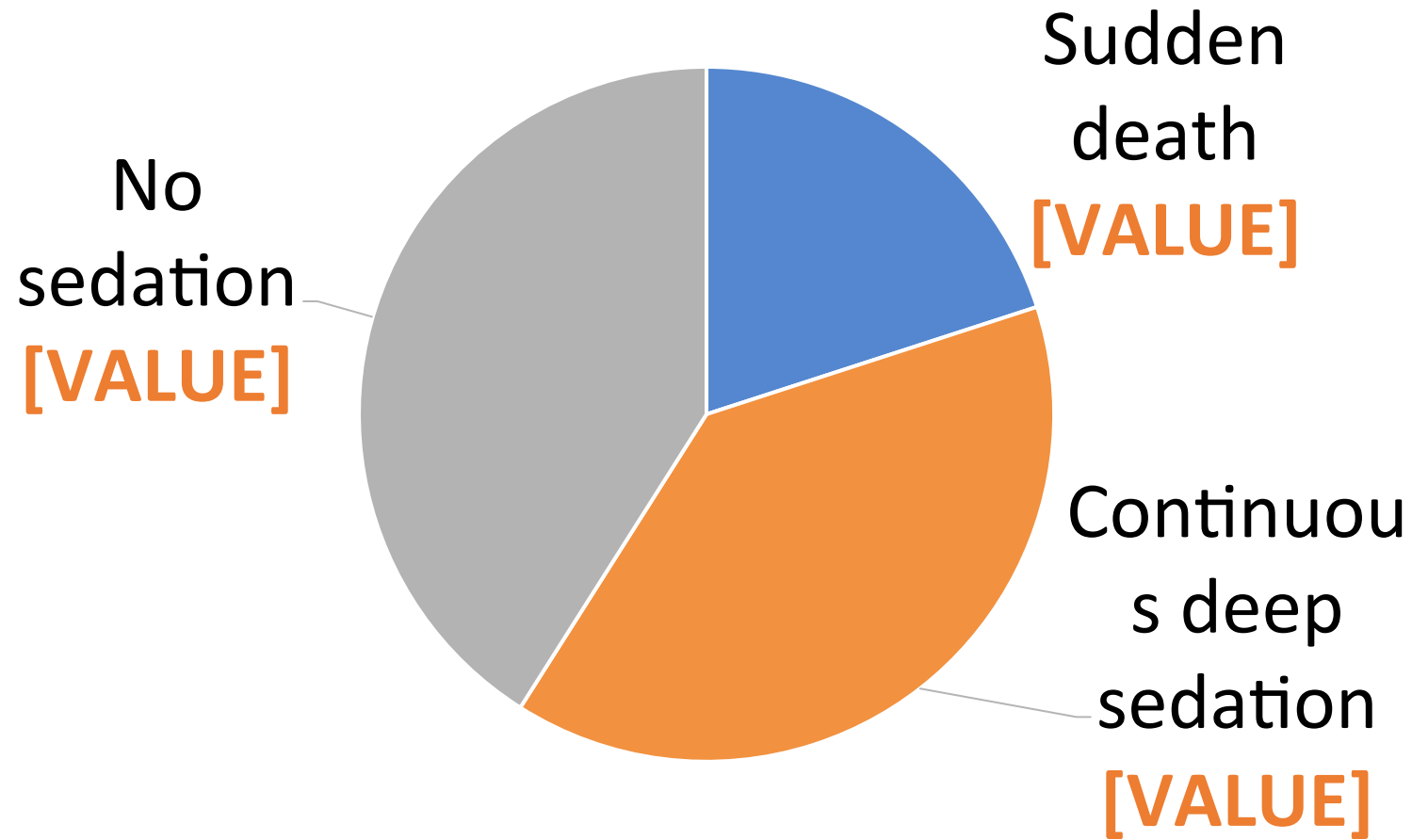
Older than 7 days → increased prevalence

P-value = 0.03

P-value = 0.003



Main results: **continuous deep sedation until death**



Most prevalent characteristics of sedation <1 year old:

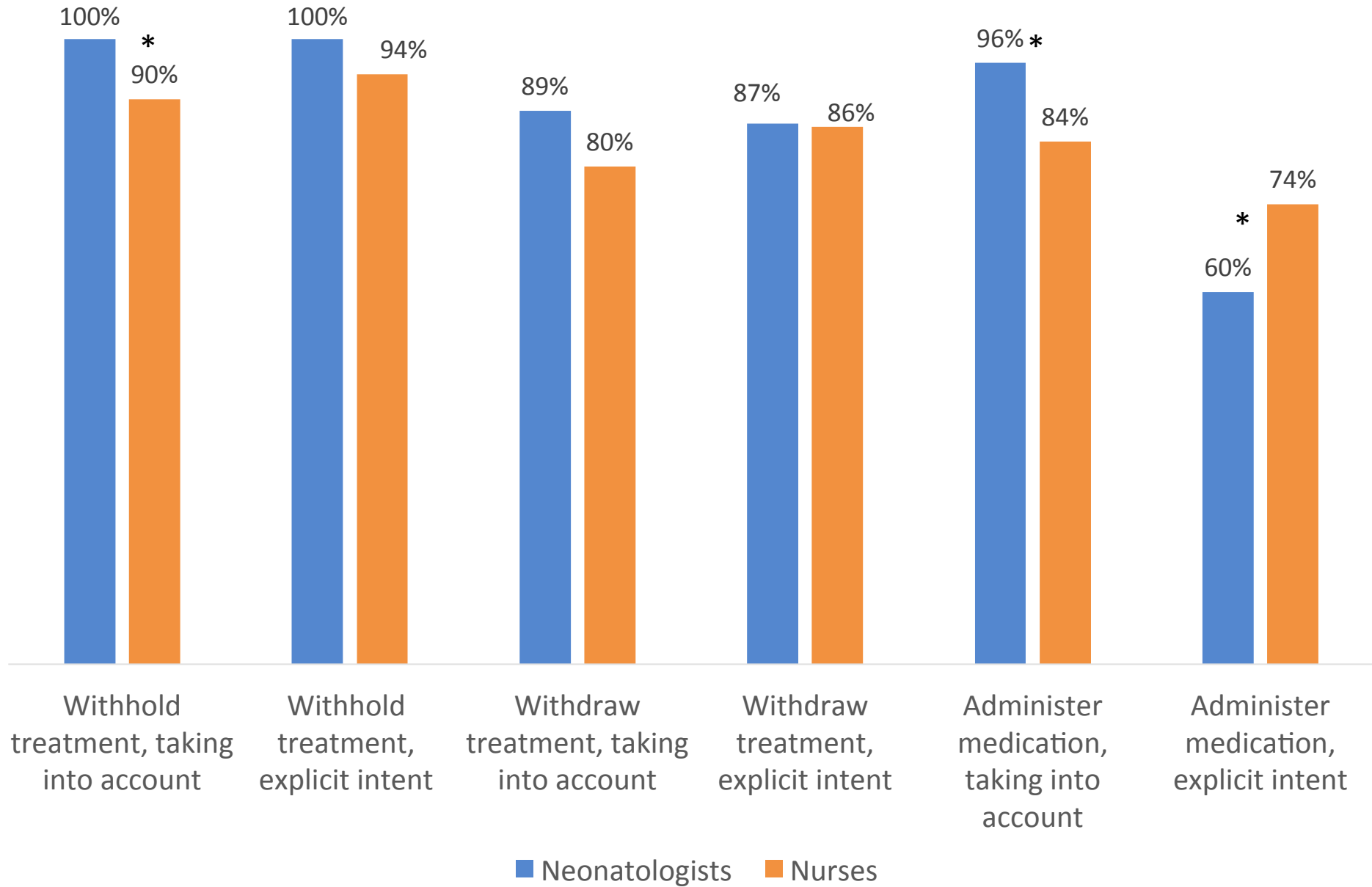
- Death occurred within one week
- Artificial nutrition and hydration provided until death
- Morphine or combination of morphine and benzodiazepines used
- 2/5 cases death was foreseen but not intended by the sedation → Is hastening death undesirable?

Prevalence estimates available → what is next?

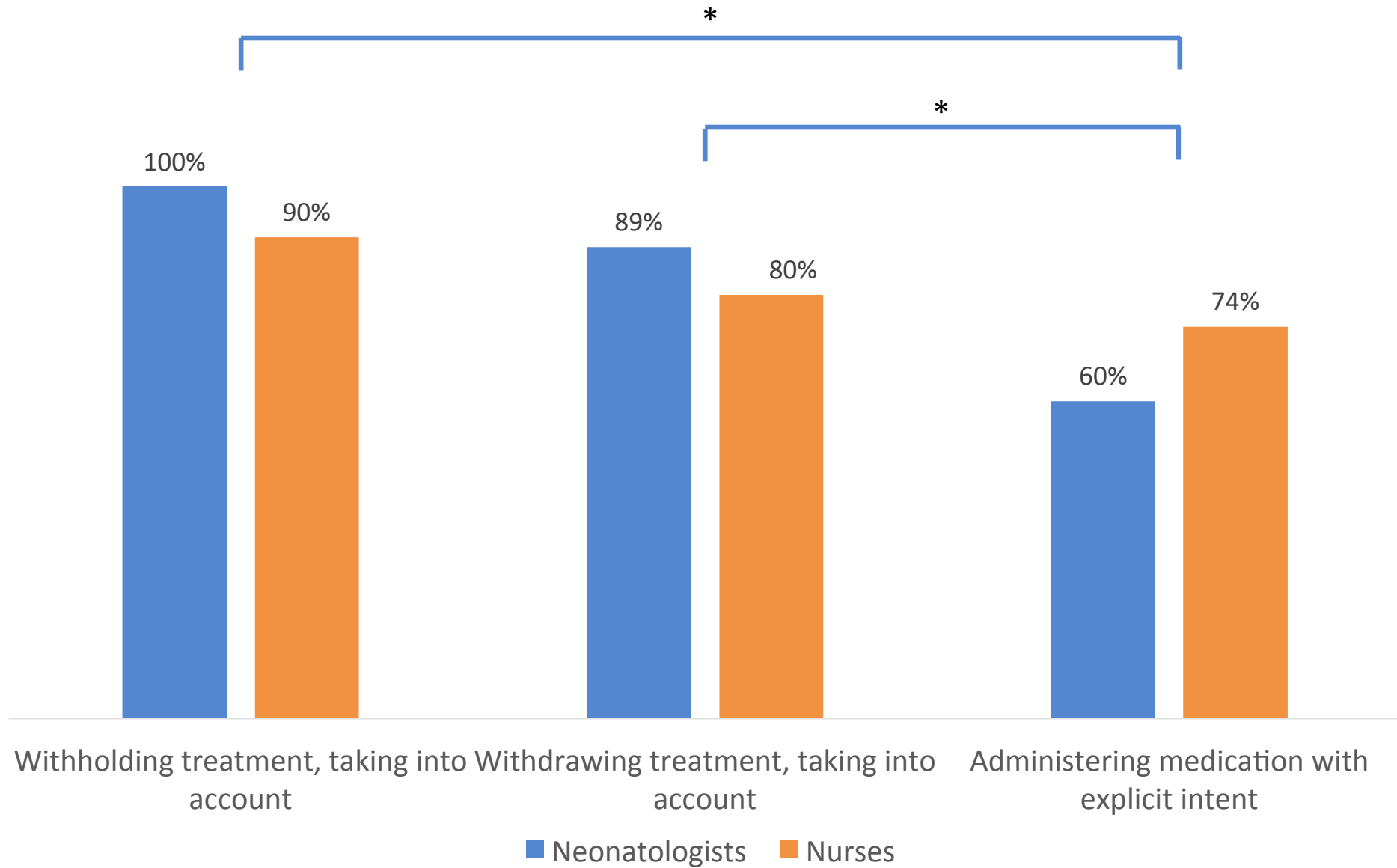
- Attitudes of healthcare providers
- Stress and resilience of healthcare providers
- Communication between actors

Attitudes of healthcare providers

ELDs in neonates are considered highly acceptable by HCPs

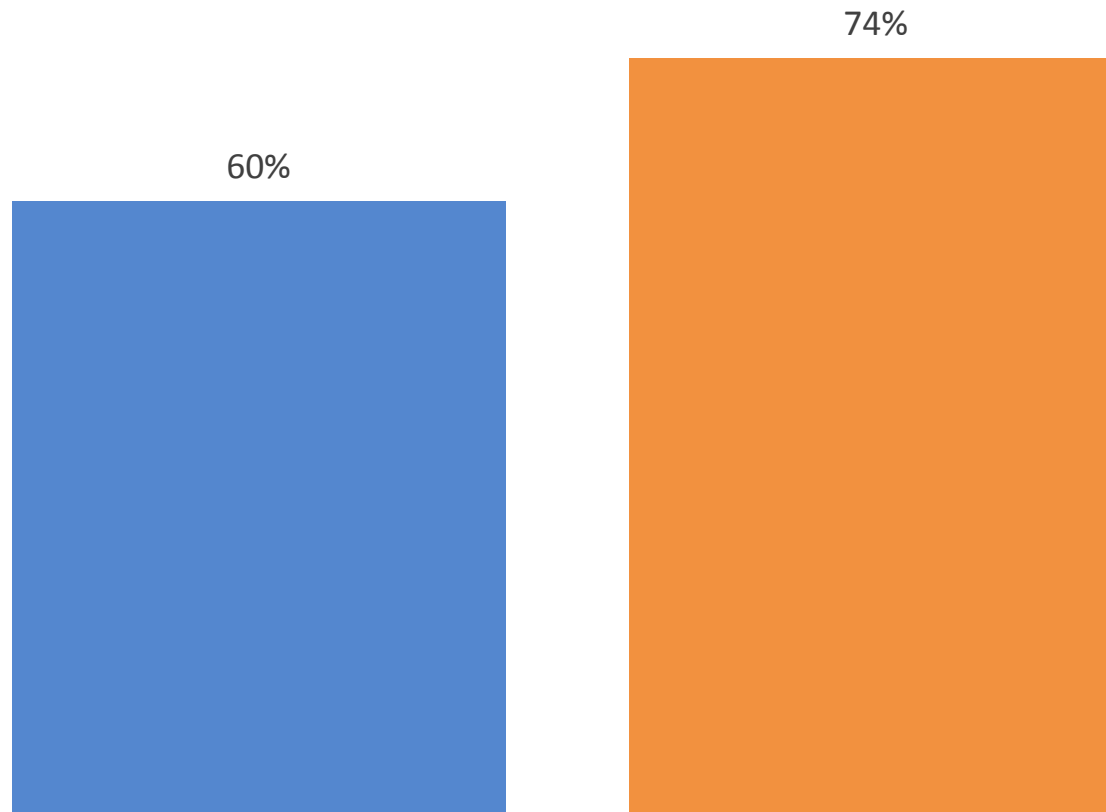


Difference in acceptability of non-treatment decisions with a possibly life-shortening effect VS 'active ELDs' using medication



Difference in acceptability of 'active ELDs' between physicians and nurses

■ Neonatologists ■ Nurses

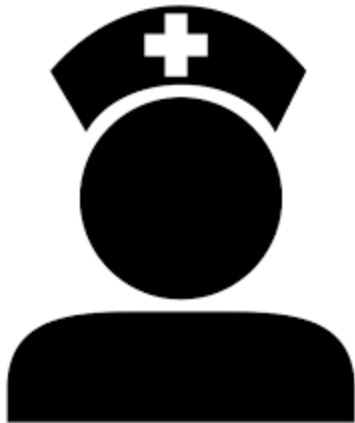


Administering medication with explicit life-shortening intention



Responsibility for the (illegal) decision?

OR



Nurses more often confronted with suffering of the child?

Stress and resilience of healthcare providers

■ Neonatologists

■ Nurses

73%

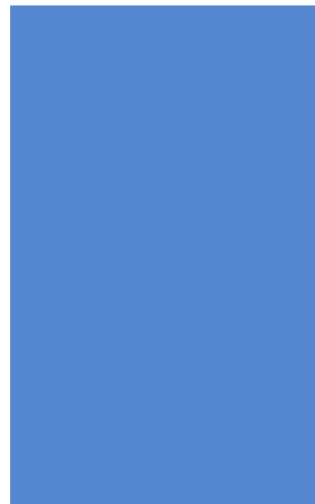
70%

94%

92%

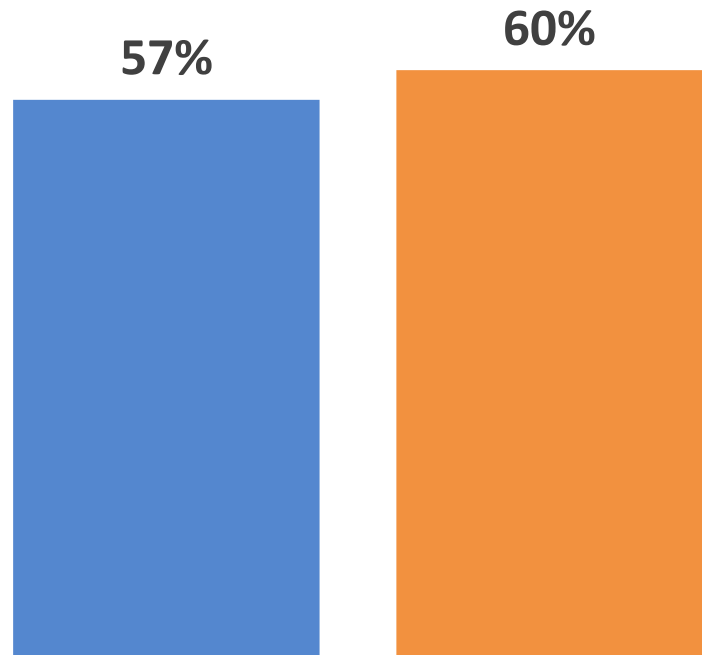
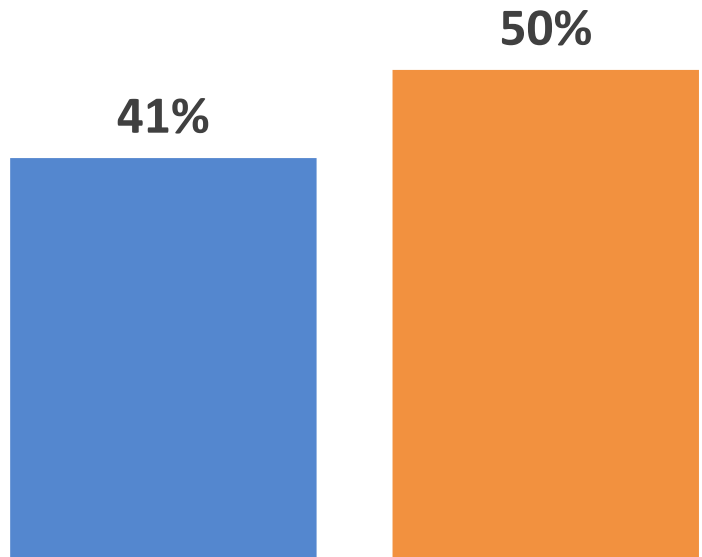
ELDs cause more stress than usual

When something is bothering me regarding ELDs, I can talk to colleagues about it



■ Neonatologists

■ Nurses



I receive sufficient psychological support from my department after a patient died

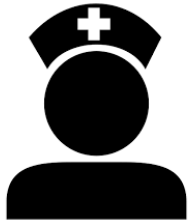
I would like my department to offer more psychological help to staff when confronted with an ELD

Communication between actors

Shared decision-making

Surrogate is needed to make decisions

Shared decision-making is recommended



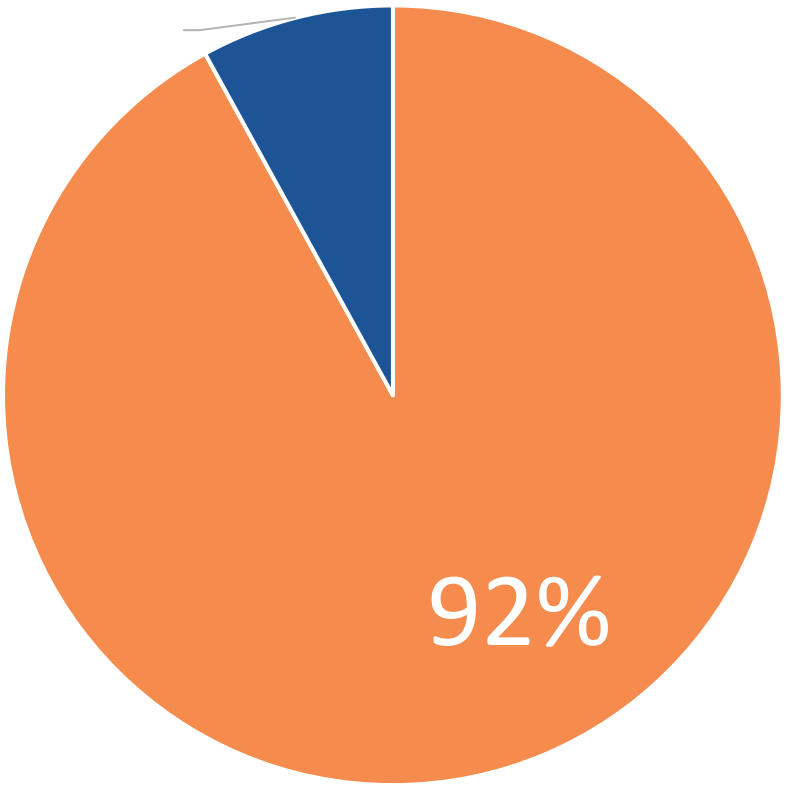
Medical team (individual roles)

- Physicians
- Nurses
- Specialists
- Other (para)medical personnel

Parents

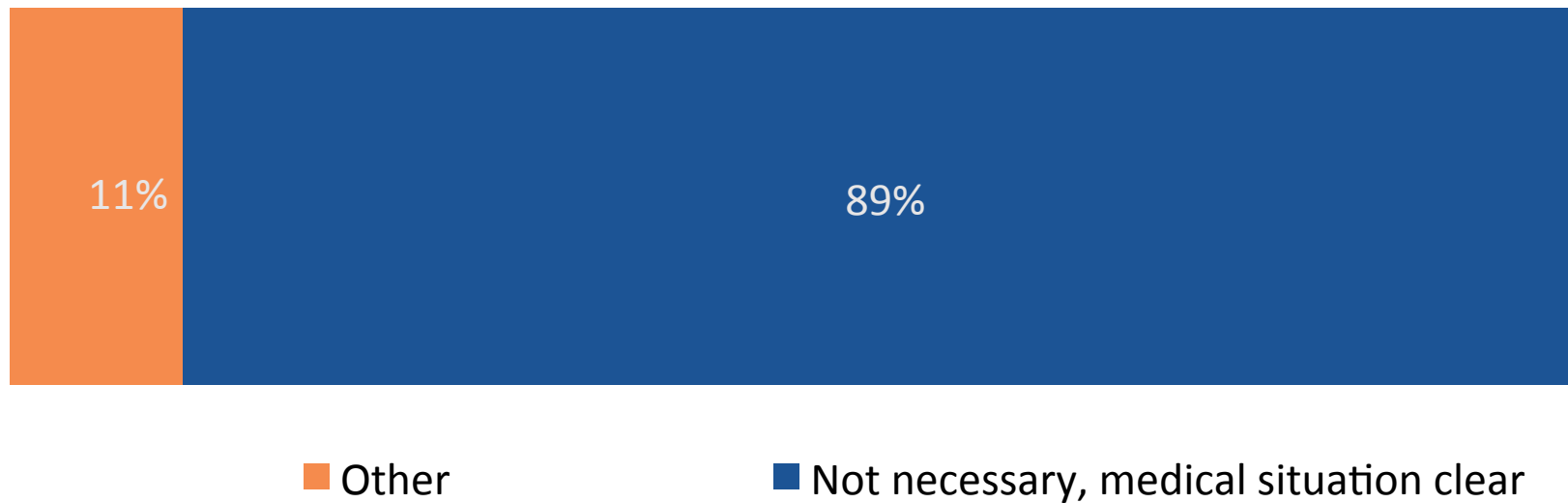
- Sometimes other supporting relatives/friends

Parents are almost always involved in decision-making



■ Parents consulted ■ Parents not consulted

In case parents were not consulted



Which decisions?

- 36% non-treatment decision
- 64% medication without explicit life-shortening intention (comfort medication)

What do parents have to say?

Parents who understand the diagnosis and prognosis → facilitator in decision-making

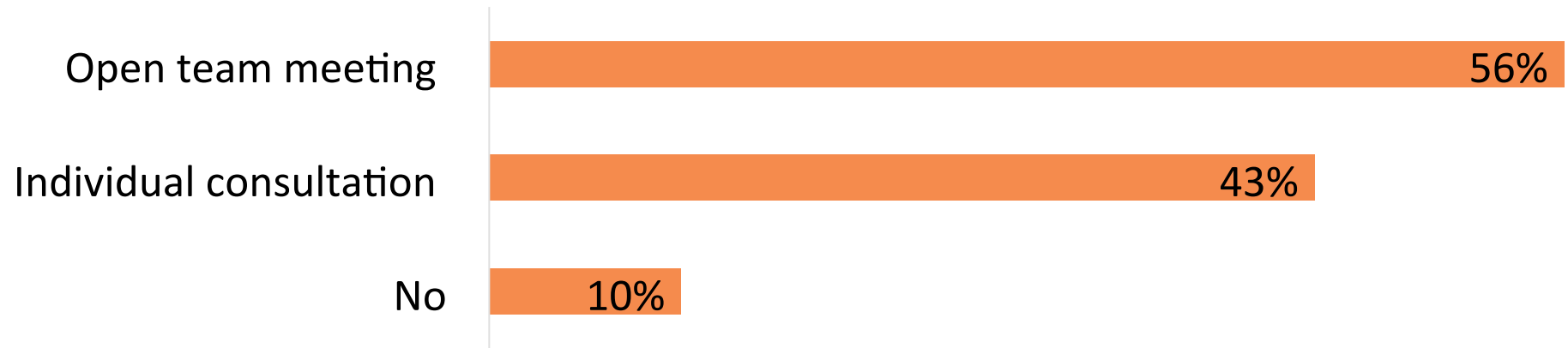
Adapt communication of HCPs to knowledge level of parents

- Mirror terminology
- Honesty and transparency
- Always check norms, wishes, concerns,... of parents

Intense emotions hinder understanding → REPEAT!!!

Dangerous pitfalls: parents have the right not to know

Consultation of other healthcare providers in decision-making

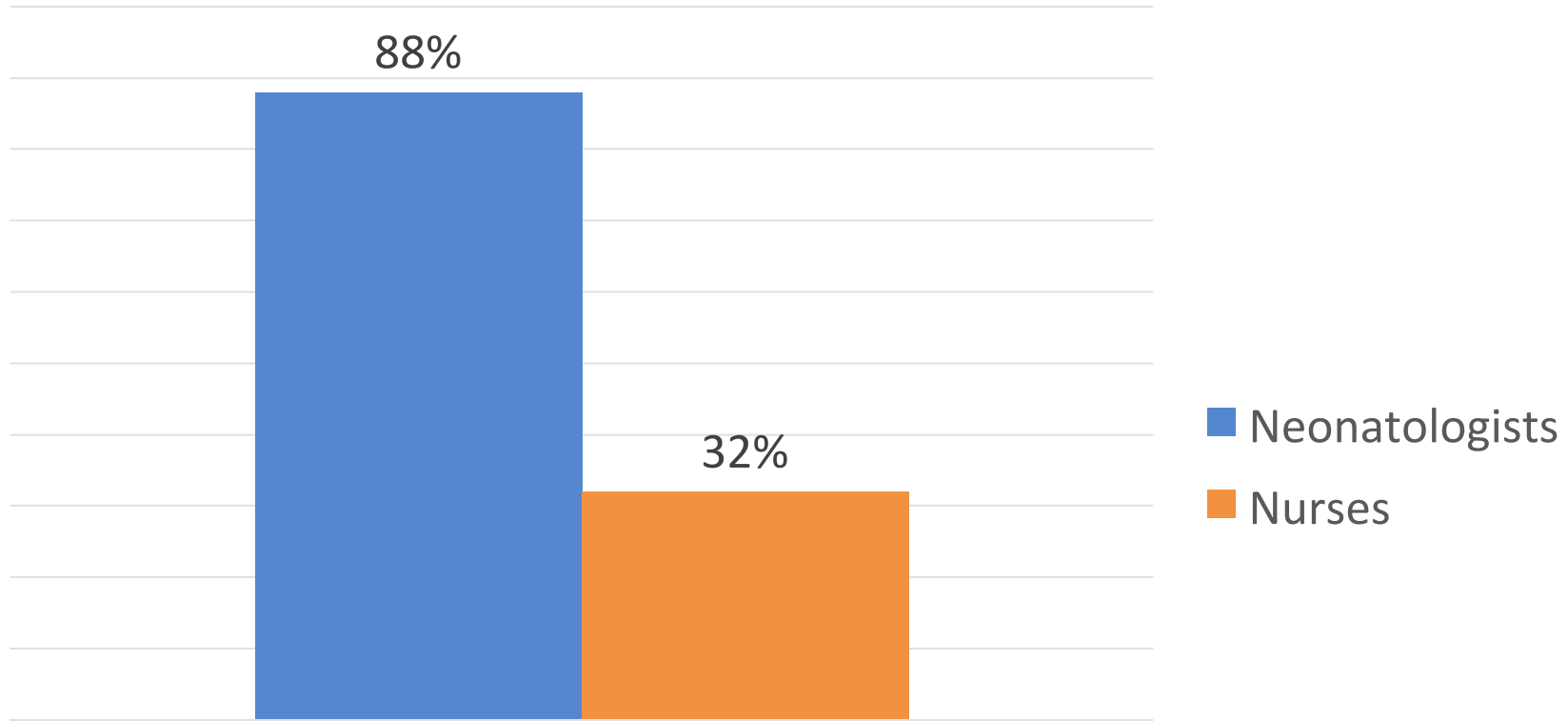


Who is consulted?

Neonatologist	71%
Nurse	42%
Pediatrician	30%
Other physician	27%
Gyneacologist	20%
Family (other than parents)	11%
Other	3%

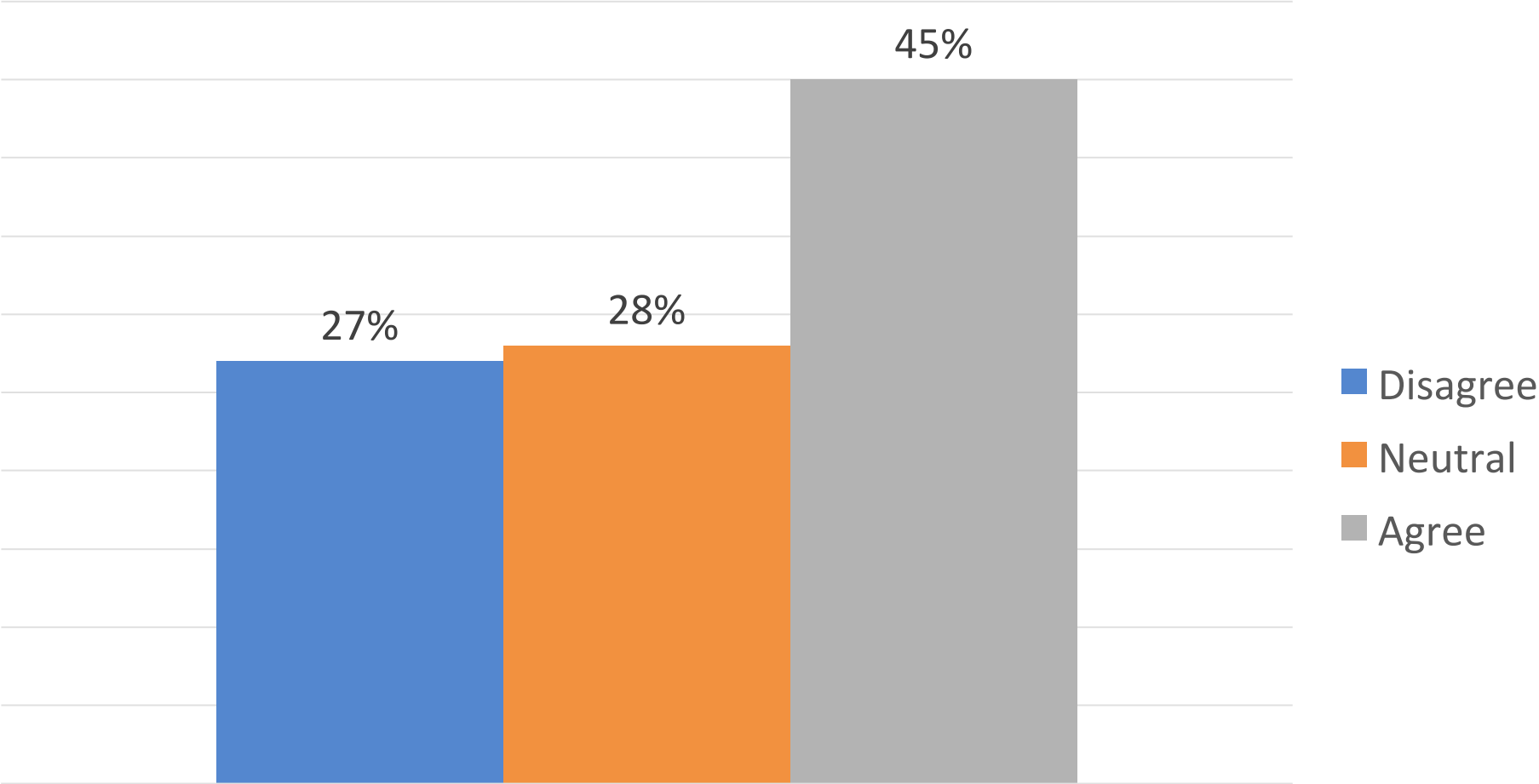
Ethical committee in only 2% of cases

Physicians versus nurses → other experiences



Sufficient opportunities are offered by the department to express my possible objections to end-of-life decisions

Less than half of all nurses feel heard by the physician



I feel that the treating physician(s) listens to my opinion when making an end-of-life decision

What do healthcare providers have to say?

Not being involved in decision-making is problematic

Multidisciplinary consultation is key

- Reduce uncertainty, provide opportunities to disagree/step away
- Involvement of nurses is more difficult

Debriefings

- Provide opportunities to learn and discuss alternatives
- Often skipped due to lack of time

Conclusion: Good starting point but a lot left to learn

Questions?

