Core outcomes sets within FICare research

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All pictures with consent of parents

Disclaimer

Epidemiologist

MD

PhD-student

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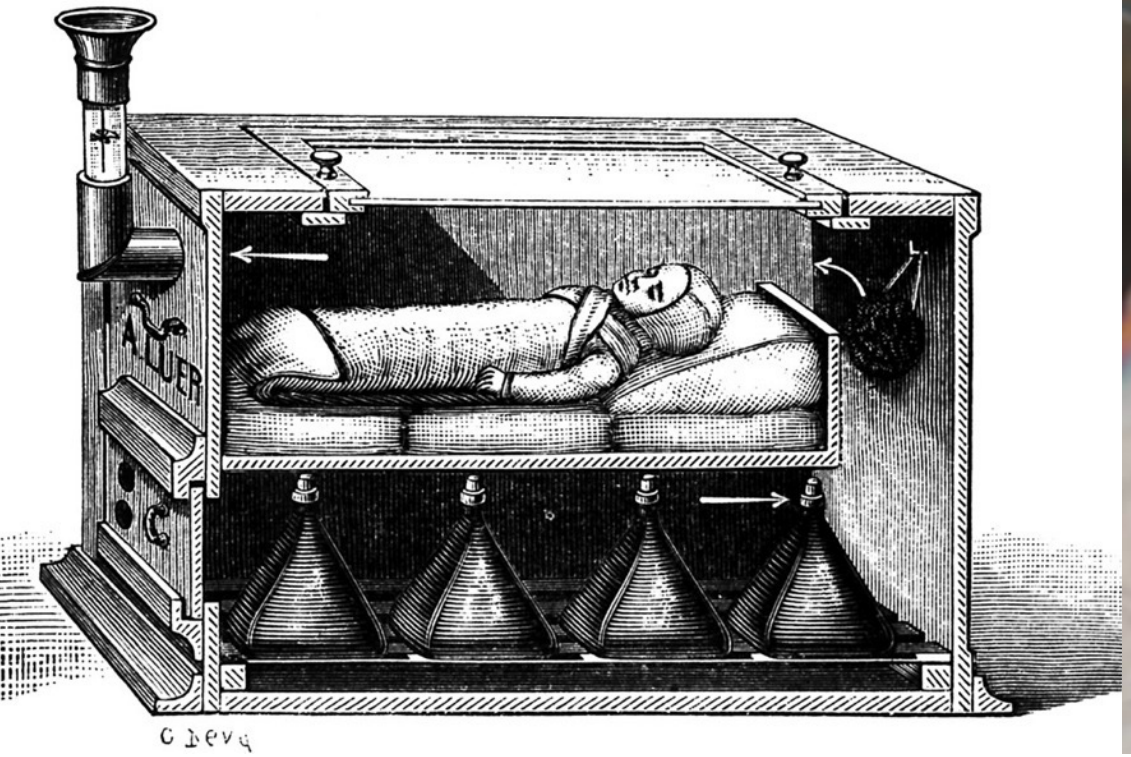
Disclaimer

Problem encountered vs. solution vs. proposal



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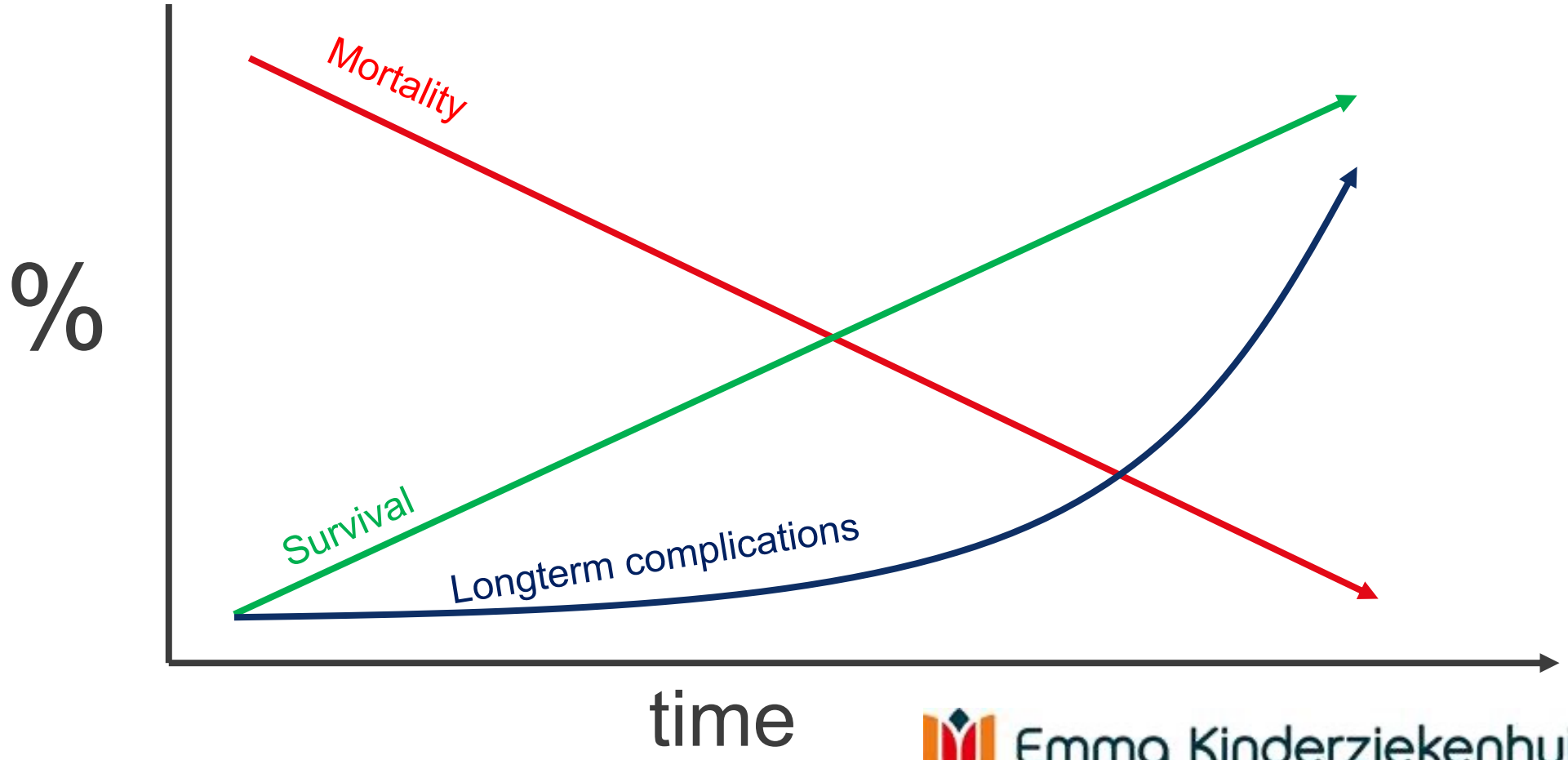
PHILIPS

Family integrated care – what do we know?



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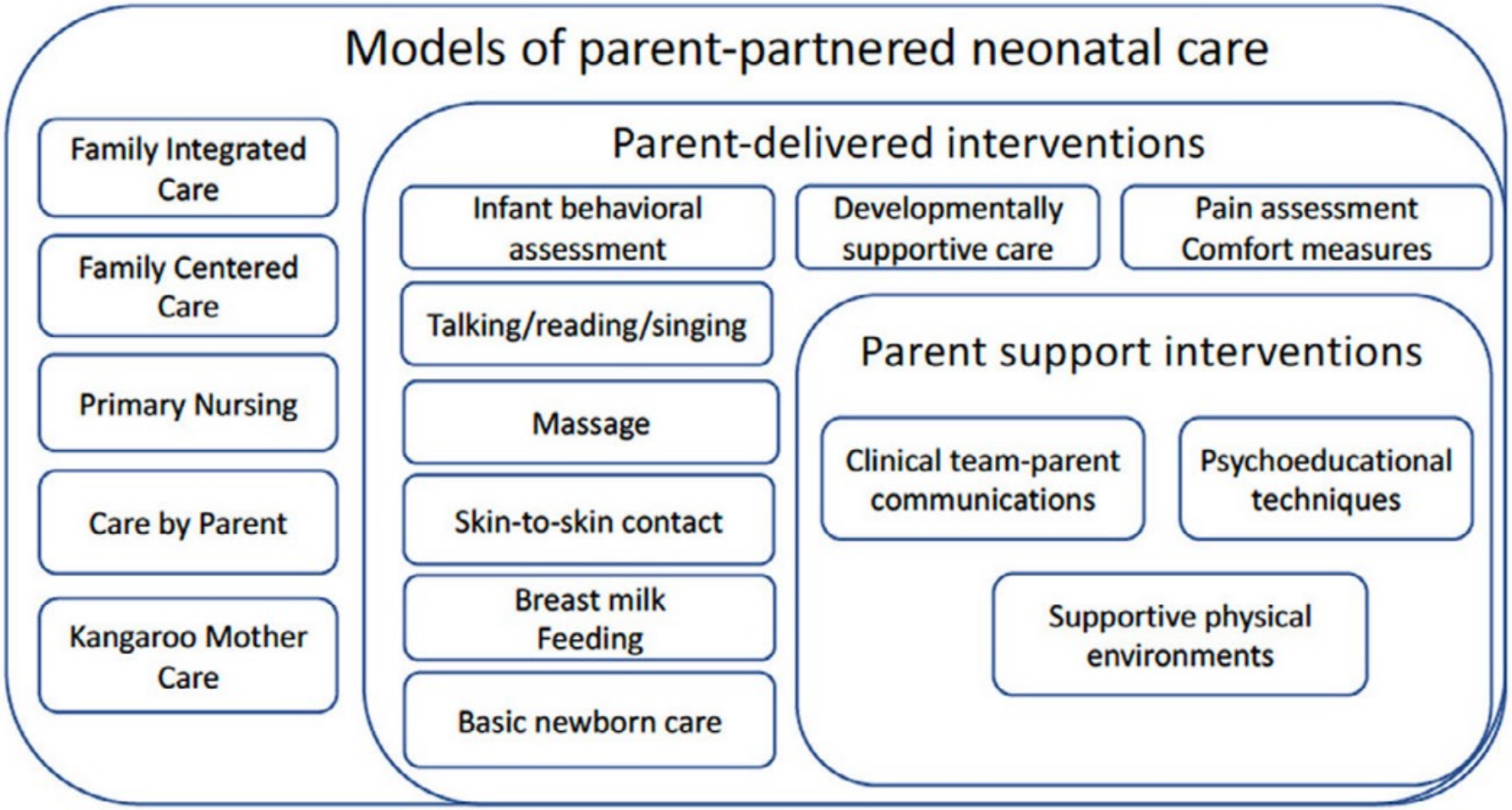

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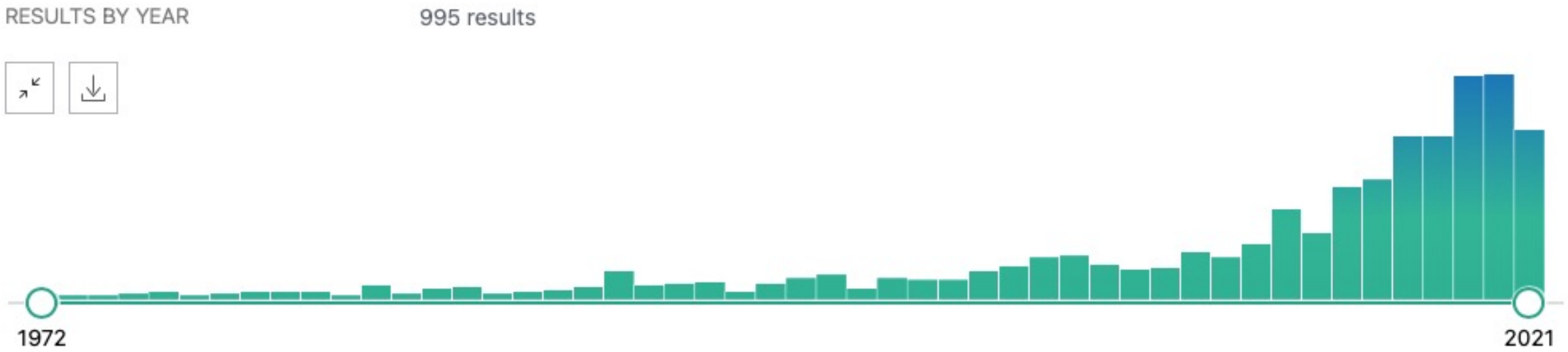
FICare research



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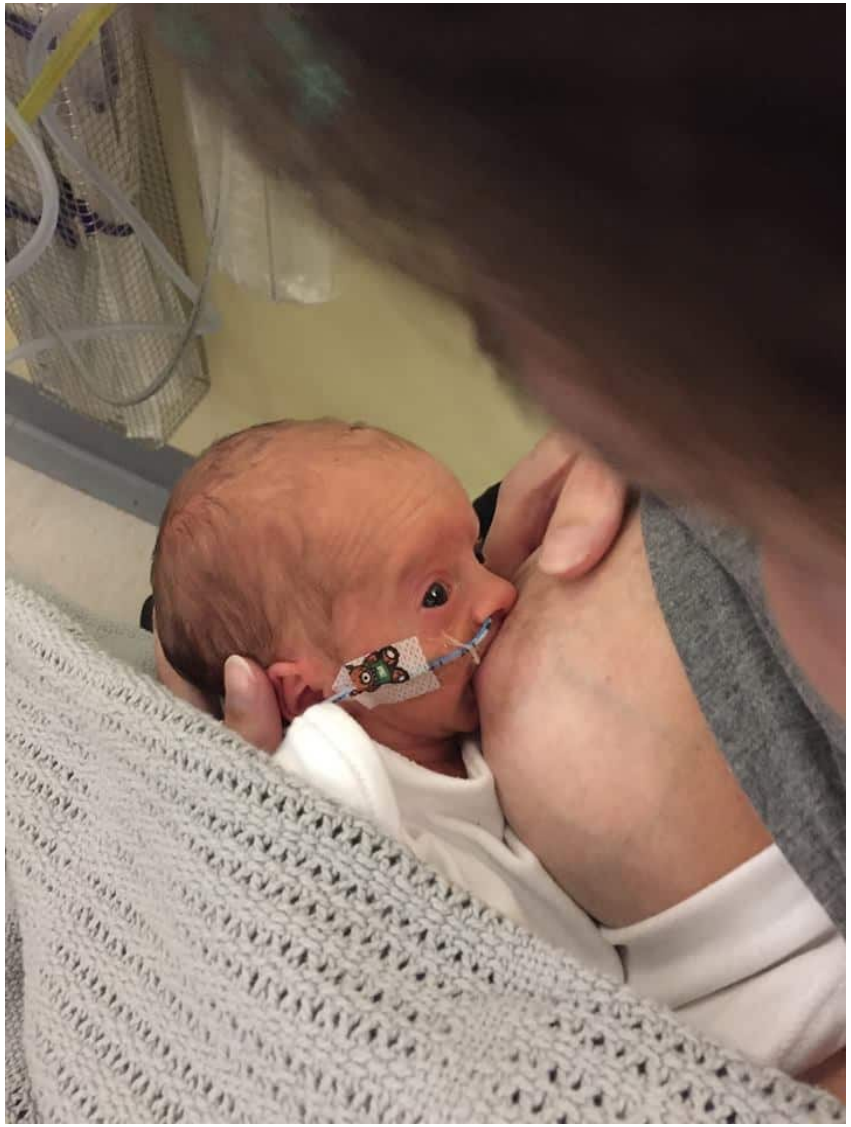
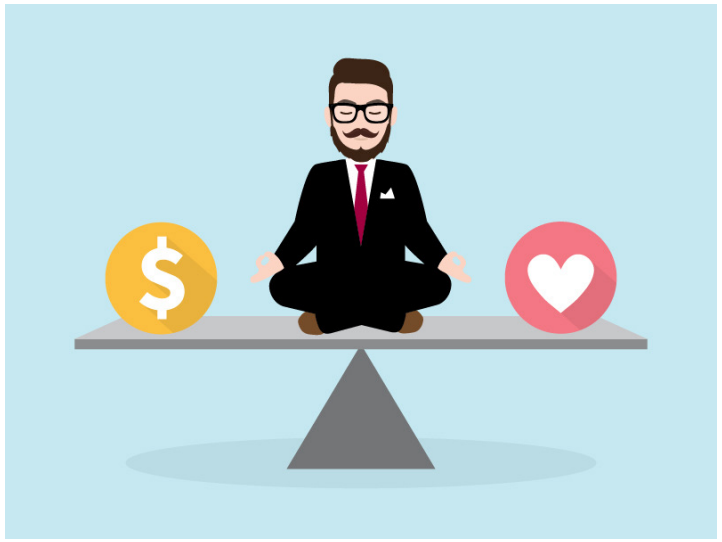
Outcomes





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Neuro-develop-ment (long term, >9 months)	Neuro-develop-ment (during hospital stay)	Length of hospital stay	Sepsis	Breast-feeding at dis-charge	Mortality	Growth	IVH	BPD	ROP
..	..	Yes	Yes	..	Yes	Yes	Yes	Yes	Yes
..	..	Yes	..	Yes	Yes	Yes	..	..	..
..	..	Yes	Yes	..	Yes	..	Yes	Yes	Yes
..	..	..	..	Yes	..	..	..	..	..
..	..	Yes	Yes	Yes	Yes	Yes	..	..	..
..	..	Yes	Yes	..	Yes	..	Yes	Yes	Yes
..	..	Yes	..	..	..	Yes	..	..	..
..	..	Yes	Yes	Yes	..	..	Yes	..	..
Yes	Yes	Yes	Yes	..	Yes	..	Yes	Yes	Yes
Yes	Yes	Yes	Yes	..	..	..	..	Yes	..
..	..	Yes	Yes	Yes	..	..	..	..	..
..	..	..	Yes	Yes	..	..	..	..	..
..	..	Yes	..	..	..	..	..	..	..
..	Yes	Yes	Yes	..	..	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	..	..	Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
..	..	Yes	..	Yes	..	Yes	..	..	..
..	..	Yes	..	Yes	..	..	..	..	..
..	..	Yes	Yes	..	..	..	..	..	..

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Van Veenendaal NR et al. Lancet Child Adolesc Heal. 2019 Mar;3(3):147–57.

Stress at discharge	Stress after discharge	Anxiety at discharge	Anxiety after discharge	Depression at discharge	Despression after discharge	Self-efficacy, empowerment and use of resources	Satisfaction	Family-centred care	Parent-infant bonding
–	–	–	–	–	–	–	Y	–	–
–	–	–	–	–	–	Y	–	–	–
–	PSI-SF	–	–	–	EPDS	–	–	–	–
Biomarker	–	–	–	–	–	–	–	–	–
PSS-NICU†	–	STAI	–	EPDS	–	–	–	–	–
–	–	–	–	–	–	Y	–	–	–
–	SPSQ	–	–	–	–	–	–	–	–
PSS-NICU	–	–	–	–	–	–	PG	FCCS	–
PSS-NICU	–	–	–	BDI	–	–	–	–	–
–	–	–	–	–	–	–	–	–	–
–	–	–	–	–	–	–	–	–	–
PSS-NICU, DASS-21	DASS-21	DASS-21	DASS-21	DASS-21	DASS-21	PES	–	–	–
–	–	–	–	–	–	–	–	–	–
–	–	–	–	–	–	–	Y	Y	–
–	–	–	–	–	–	–	–	Y	–
PSS-NICU,	PSI-SF	STAI-SF	STAI-SF	EPDS	EPDS	–	–	–	MPAS

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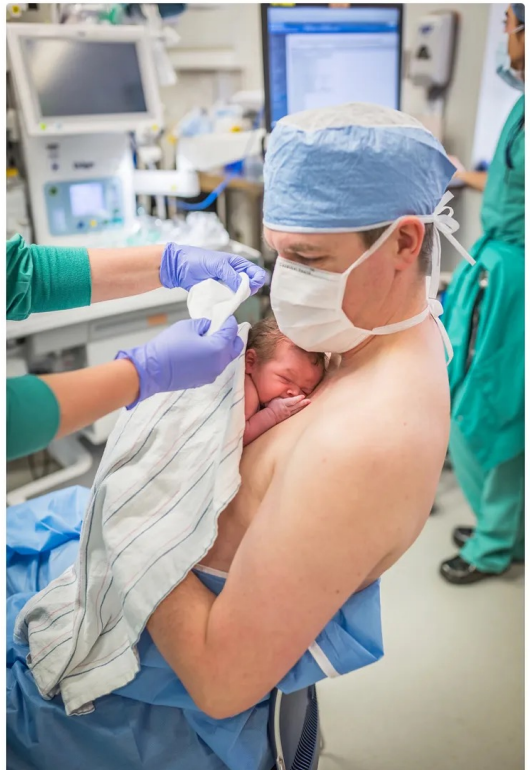
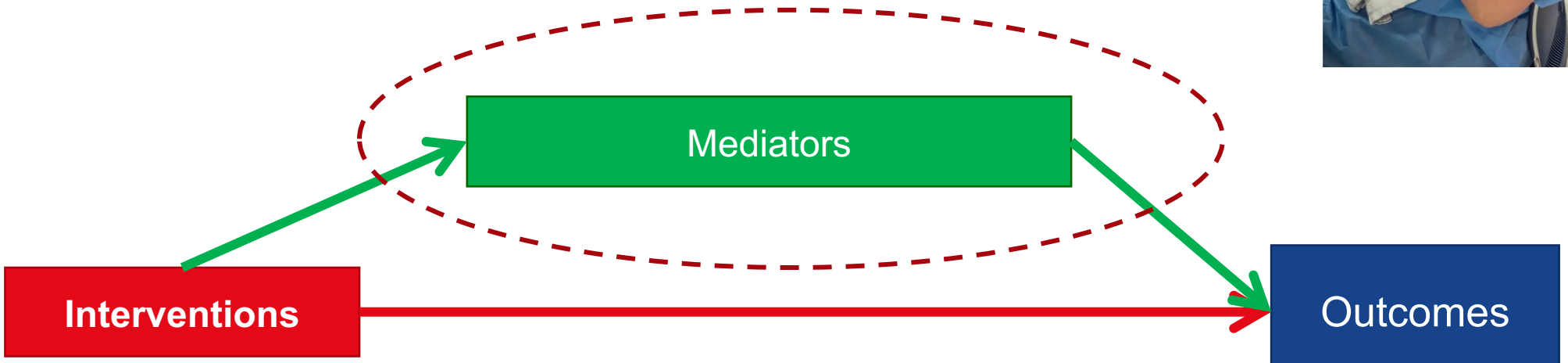
van Veenendaal NR, et al. EClinicalMedicine. 2020

Mediators





What is the problem?

- Non-comparable studies
- Only publish some results (for instance that are “significant”)
- Not all results are available, which could be pooled in systematic reviews / meta-analyses
- “Bias”

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Potential solution

Core outcome sets

- All studies use the same outcomes (independent of their significance or value)

- Definition of outcomes through rigorous methodology
  - Systematic review
  - Delphi study
  - Consensus meeting

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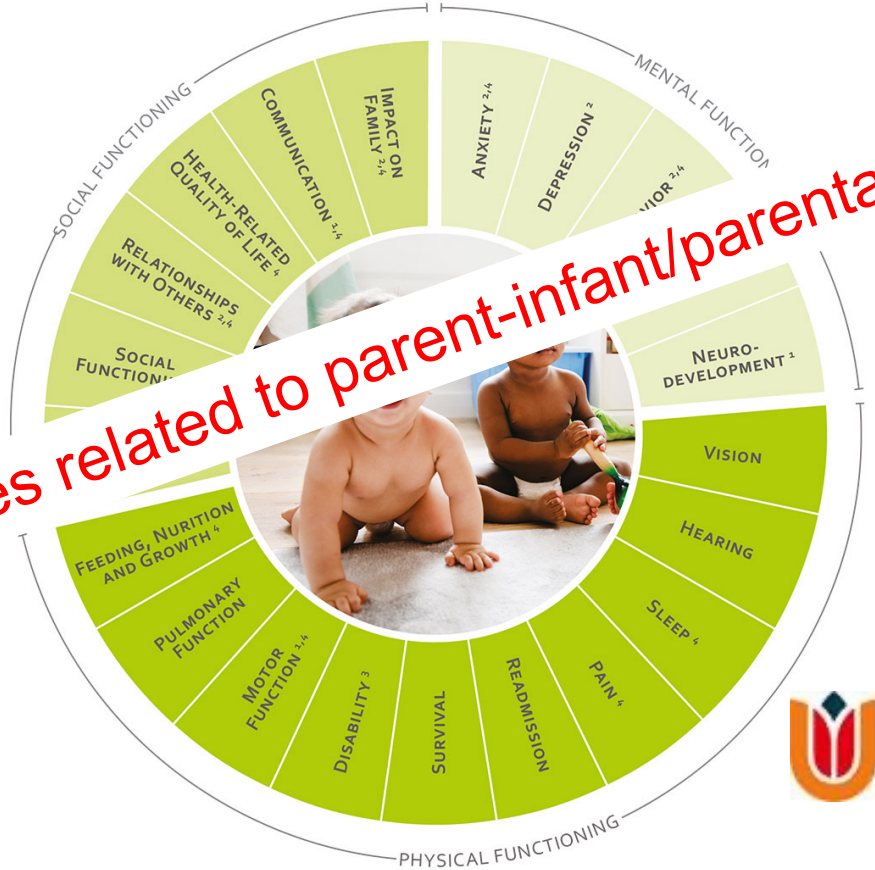
Potential solution

Core outcome sets

No outcomes related to parent-infant/parental experiences in the NICU

Neonatal palliative care



Core C
In N atology

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Potential solution – but how?

Establish core outcome set for family interventions research in neonatal care

- Patients
- Healthcare providers
- Other experts

https://www.comet-initiative.org/Studies/Details/1925

Provide meaningful outcomes in research surrounding FICare and family interventions

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Plan of action

January 2022: Formation of steering group for COS in FICare
- Protocol
- Systematic review
- Delphi study

Sign up (Delphi / steering group).
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Disclaimer: *maternity leave*.

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