

Using published research to extract parent and patient outcomes

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Outcomes in Neonatal Medicine

Outcomes crucial in neonatal medicine

- ROP
- Antenatal steroids



At present:

- 47% of recent Cochrane reviews ‘inconclusive’
Willhelm et al. Paediatrics and neonatology. 2013
- This proportion is increasing

Identifying Important Outcomes

Identify key stakeholders

- Patients, parents and clinicians

Identify which outcomes they report are important

Gorst et al. PLoS ONE 2016

- Meetings/teleconferences
- Nominal Group Technique/Focus Groups
- Delphi

Stakeholders' views have never been sought by systematic review of existing research

Our aim

To review published qualitative research to identify outcomes important to patients, parents and clinicians

Rationale

Reviewing existing literature will:

- Allow us to access a diverse range of viewpoints from a diverse range of stakeholders
- Avoid duplication of existing research
- Ensure time of patients and parents is not wasted

Methods

We searched:

- Medline
- CINAHL
- EMBASE
- PSYCINFO
- ASSIA

Completed, peer-reviewed papers considered

Eligibility Criteria

Sample:

- Babies requiring care in a neonatal unit (NICU/SCBU)

Phenomenon of Interest:

- Neonatal intensive care

Design:

- Qualitative study or quantitative study that has also collected qualitative data

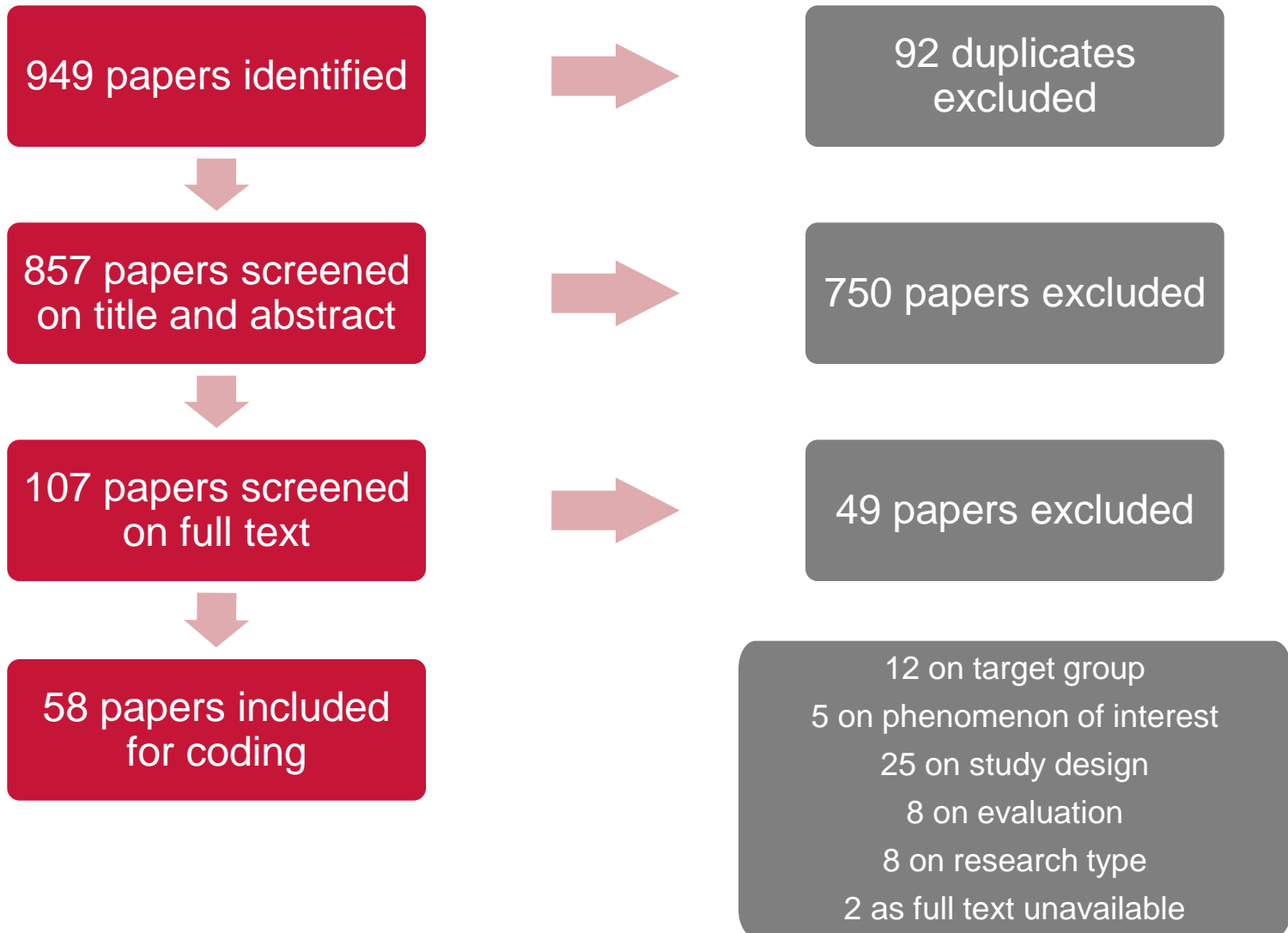
Evaluation:

- Study must include qualitative data relating to which outcomes stakeholders feel are important

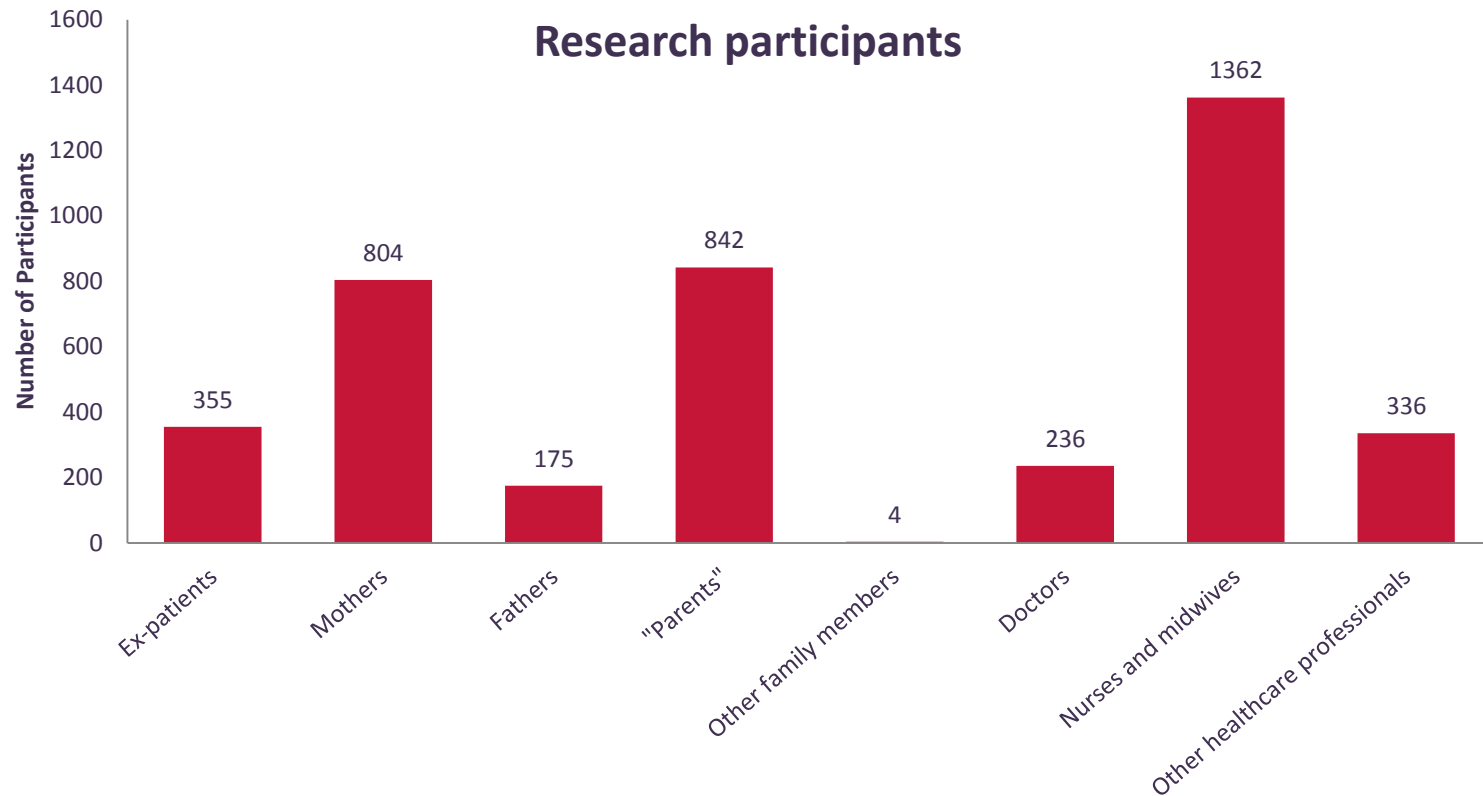
Research type:

- Qualitative/mixed methods

Results



Results

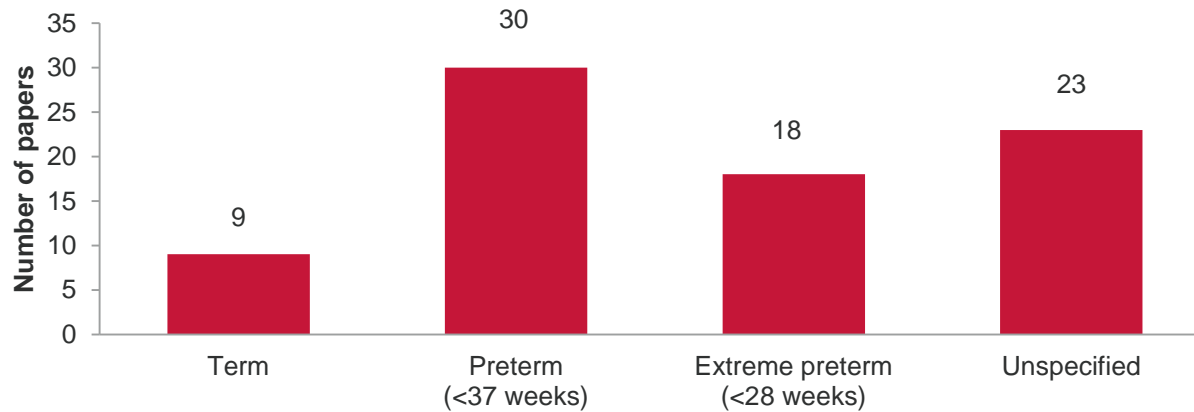


Other family members: grandmothers, uncles

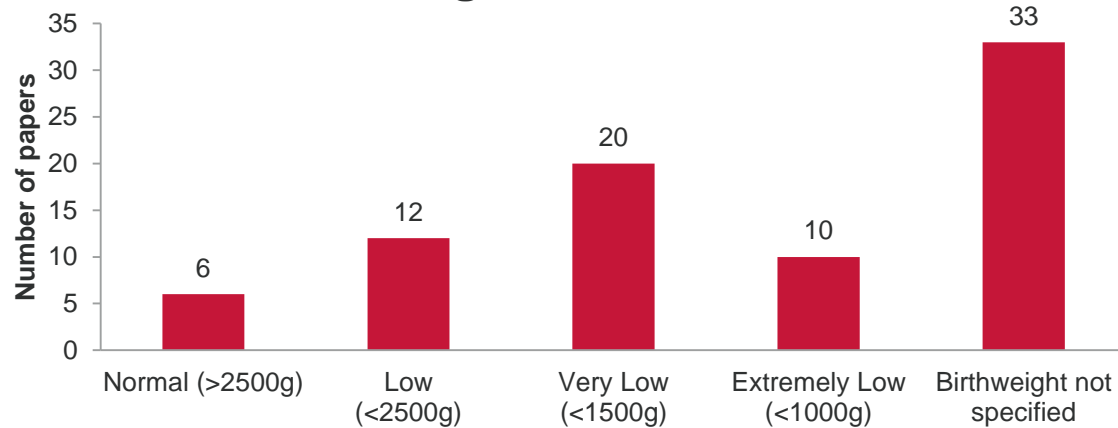
Other healthcare professionals: teachers, social workers, pharmacists, occupational therapists, physiotherapists etc.

Results

Gestational age of infants

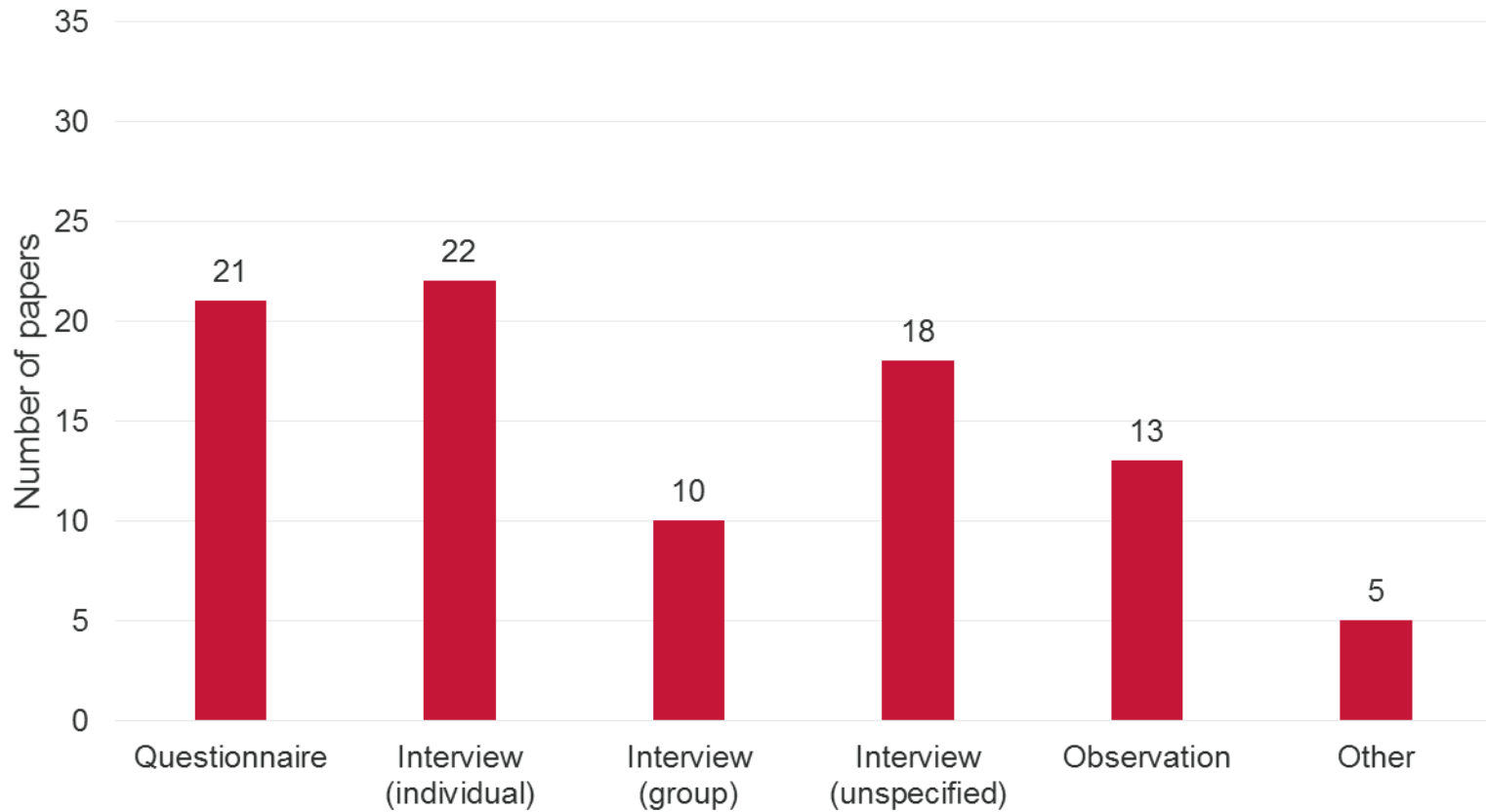


Birthweight of infants



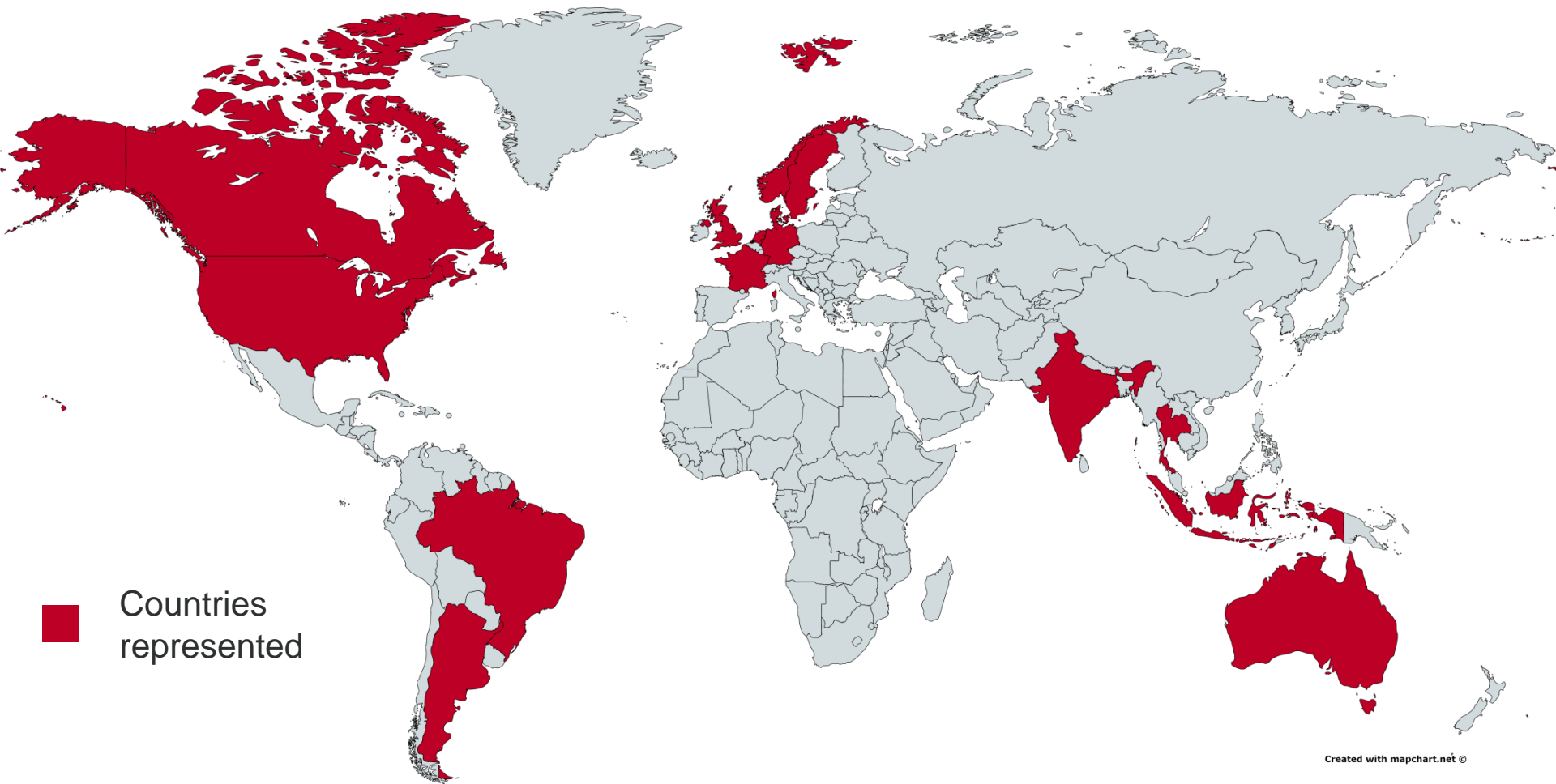
Results

Methodology of papers



Results

International sample:



Results: Outcomes

58 papers

186 discrete outcomes

- 69 related to 'physiological systems'

	Number of Discrete Outcomes	Number of Studies
Cardiovascular	2	1
Respiratory	18	12
Gastrointestinal	14	22
Neurological	6	8
Genitourinary	1	1
Infection	3	5
Skin	5	4
Surgical	4	5
Developmental	16	30

Outcomes: Gastrointestinal

Most commonly identified outcomes:

- Breastfeeding

"I'm glad I'm doing it. I feel good that I'm doing it. I feel good about myself. It makes me feel good about myself that I'm doing it for him."

"Because I think I understood the importance of what my wife was trying to do. It was extremely important for our babies, who are very fragile and sick, to receive breast milk."

- Oral feeding

"(The) very first time (feeding the baby) was just great, to tell you the truth. It was an experience, just like, 'Wow'...it was just looking into him and just like, 'wow, look what we made, 'know?' It was just crazy...it was just wonderful."

"the only concern I have is, I don't want them to choke.-I'm fearful of choking."

Results: Outcomes

117 other outcomes

	Number of Discrete Outcomes	Number of studies
Parental support	17	28
Healthcare utilisation	7	14
Healthcare professionals: Communication	21	27
Healthcare professionals: Knowledge and Competence	14	21
Psychosocial(medical)	8	7
Psychosocial (non-clinical)	12	19
Pain	3	6
Suffering	4	15
Normality	6	20
Survival	12	17
Physical appearance	1	7
Growth	1	8
Cost of care	2	3
Vitality	2	1
Iatrogenic harm	1	2
Inclusion in research	2	1

Less commonly reported outcomes included: Support beyond NICU; Long term effects on parents; Physiological stability; Hypothermia; Schooling; Duration of admission; Overall health state and others

Outcomes: “Suffering”

15 papers identified “suffering” as an important outcome

- Identified by all stakeholder groups
- Identified regardless of gestational age or birthweight of infant

Examples:

Suffering

"This infant's short life was never comfortable. He struggled just to breathe, day after day, month after month without relief unless he was paralyzed and heavily sedated. I frequently felt we were torturing the child just doing daily care."

Comfort

"You can almost feel what it's like in the incubator, lying on the lambskin, that it's how I would want to have laid and . . . Well, it looks very comfortable"

Strengths and Limitations of Review

Strengths

- Large number of participants across stakeholder groups
- Wide range of babies represented
- Diverse range of methodologies

Limitations

- Focus on “extreme” states
- Underrepresentation of ‘normal’ babies
- Limited to what researchers have addressed
- One step removed from stakeholders

Conclusions

Elicited the voice of key stakeholders
by a systematic review of published qualitative
research

- Efficient
- Elicited a diverse range of views

Outcomes identified differ from outcomes
currently measured

- Consistent with other stakeholder involvement
projects

Why is it important?

