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Installation of Child Death Review teams in the Eastern part of the Netherlands:

results of a feasibility study

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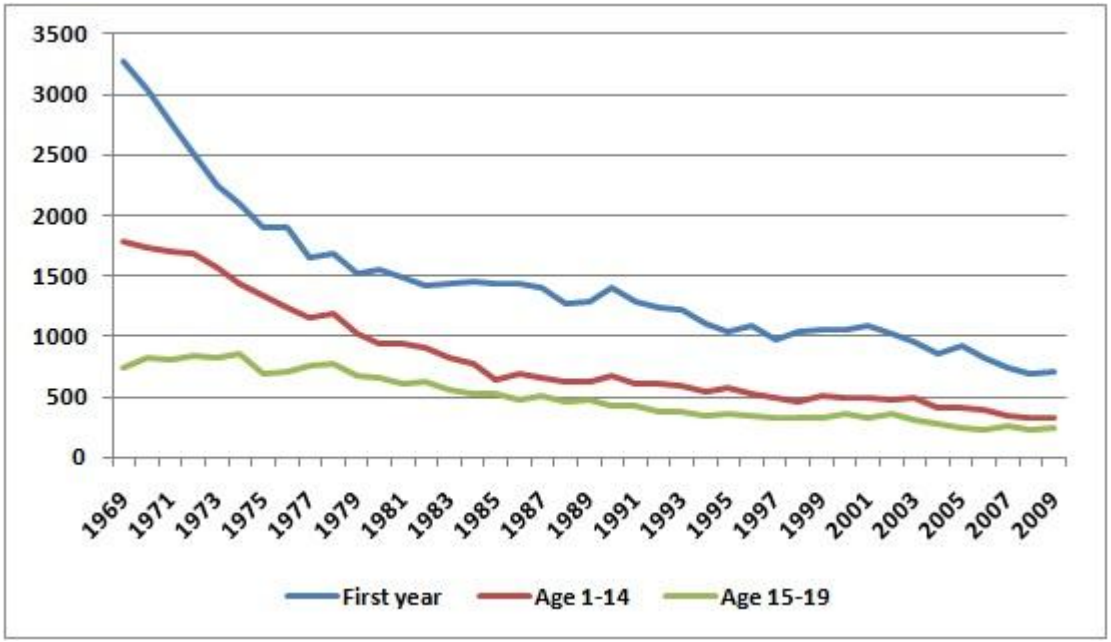
"It is important to examine the causes of child death and learn from them"

Sidebotham P, Pearson G
BMJ 2009;338:b531

Child deaths in the Netherlands 1969-2009



Source: www.fomat.nl

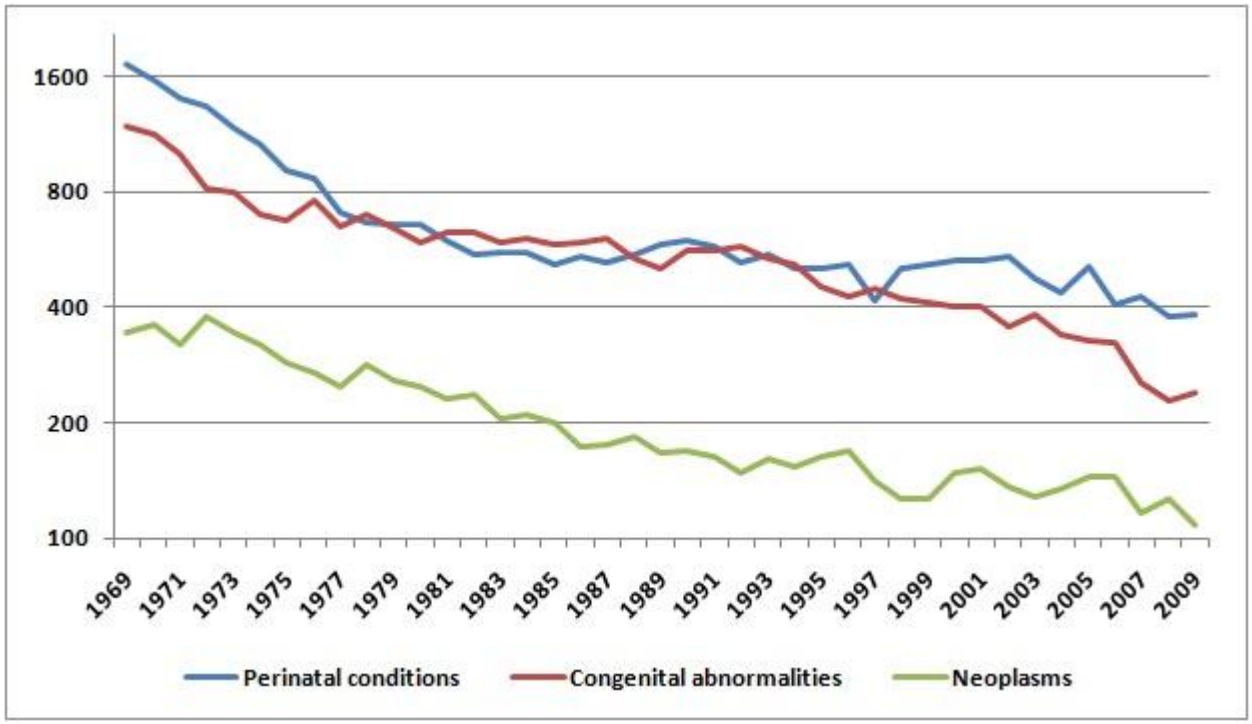
Natural causes of child death 0-19 yr 1969 - 2009

80% of child deaths are due to natural causes:

- perinatal circumstances
- congenital abnormalities
- neoplasms
- cardiovascular conditions

- and a variety of rare metabolic and nervous system disorders

Three natural causes of child death 0-19 yr 1969-2009 (logarithmic)

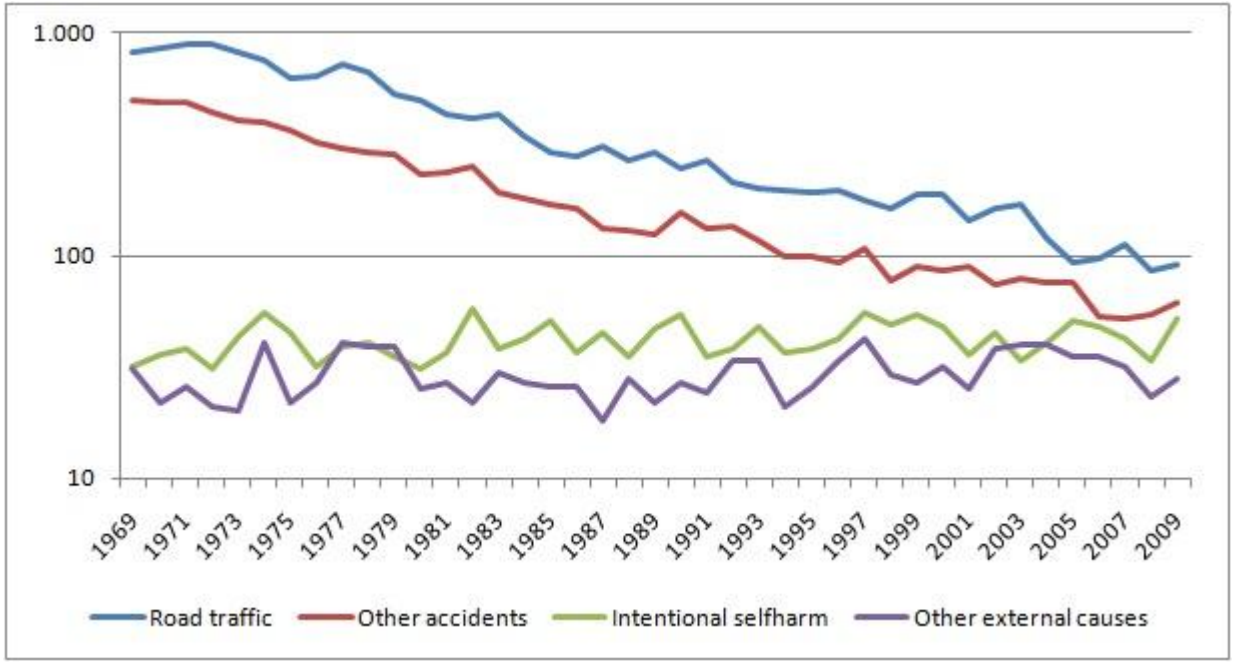


Source: www.fomat.nl

External causes of child death 0-19 yr 1969-2009

- road traffic accidents
- other accidents
- intentional self-harm
- other external causes

All external causes of child death 0-19 yr 1969-2009 (logarithmic)



Source: www.fomat.nl

Recent change in legislation

Consultation of a municipal coroner by the attending physician is mandatory in deceased minors since

1st of January 2010

Source: Dutch Burial and Cremation Act, art. 10a

"As many as 29% of child deaths may be preventable or contributed to by potentially avoidable factors"

Sidebotham P, Pearson G
BMJ 2009;338:b531

Child Death Review (CDR) in Eastern part of the Netherlands

- Preliminary study
- Feasibility study
- Data analysis and implementation strategy
- Pilot implementation

Preliminary study

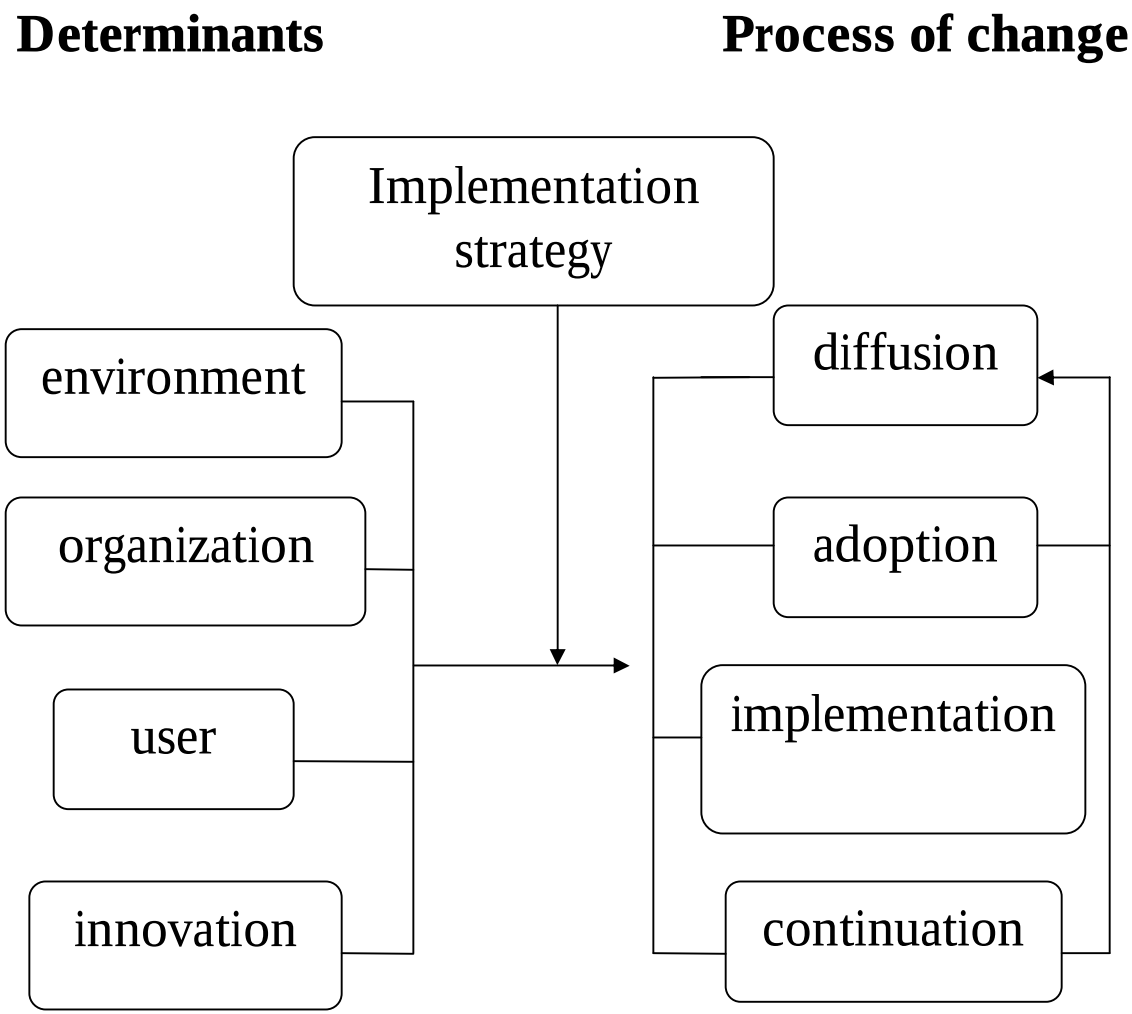
- Literature study
  - child death, causes of death, vital statistics
  - implementation of change in clinical practice
  - (inter)national methods of Child Death Review

- Introduction of the project in the pilot region
  - media attention
  - informing health care professionals

Feasibility study

- Consultation with
  - Dutch Cot Death Foundation (LWW),
  - Dutch Perinatal Audit Foundation (PAN) and
  - NODO-implementation working group (KNMG)
- Collaboration with University of Warwick (UK) and with University of Münster (Germany)
- Focus group interviews

Implementation



Source: M. Fleuren, TNO Quality of Life

Focus groups

- Focus groups: Twente / Achterhoek and Zwolle / Deventer
  - pediatrician (3-4)
  - general practitioner (1)
  - youth health care professional (1-2)
  - forensic physician (1)
  - social worker (2)
- Focus group: representatives of organizations in child and family care
- Focus group: parents of a deceased child

Determinant: Environment

Barriers for implementation:

- negative media attention
- pending NODO-procedure

Factors promoting CDR:

- increasing awareness of child death
- identification of trends/patterns
- recommendations for regional and national policy
- collaboration between professionals
- method consistent with perinatal audit

Determinant: Organization

Barriers for implementation:

- time consumption
- bureaucracy
- organizational culture difficult to change
- medicolegal consequences
- quality systems already in place

Factors promoting CDR:

- quality improvement in health care

Determinant: User (CDR team)

Barriers for implementation:

- complex medical procedures difficult to evaluate
- possible use of data by Public Prosecutor or Health Care Inspectorate
- strenuous coordination and time consumption

Factors promoting CDR:

- multidisciplinary approach
- dissemination of findings to professionals and parents
- evidence-based recommendations have more impact
- ongoing support to the family

Determinant: Innovation (CDR)

Barriers for implementation:

- issues of confidentiality
- medicolegal consequences
- involvement of the Public Prosecutor
- time consumption and bureaucracy

Factors promoting CDR:

- multidisciplinary approach
- review of every child death
- parents' consent
- support of families and professionals

Proposal for CDR in pilot region

- Pilot region: Eastern part of the Netherlands
- Target group: child deaths 29 days postpartum – 2 years, or younger, if not included in the perinatal audit
- Proposed procedure: 11 steps

Step 1: Notification

Notification through:

- youth health care
- municipal coroner
- national demographic statistics (GBA)
- pediatrician, general practitioner, others

Step 2: Informing parents

General practitioner or attending pediatrician informs the parents about the CDR procedure

(comparable with method of Dutch Cot Death Foundation)

Step 3: Contact

Coordinator CDR contacts parents and requests their cooperation

Step 4: Consent

The parents are invited to sign informed consent;
this is necessary before start of the CDR procedure and the data collection

Step 5: Intake

Approach of professionals to collect information on backgrounds and circumstances of the child's death

Step 6: Chronological report

Chronological report of the collected information by the CDR coordinator

Step 7: Data confidentiality

Data in chronological report are anonymized by the CDR coordinator

Step 8: CDR meeting preparation

Coordinator of the CDR team informs the team members that a meeting will be scheduled

Step 9: Review procedure

Procedure consistent with the perinatal audit:

- statement of confidentiality
- handout of chronological report at the meeting
- discussion and analysis of the report

Proforma analysis form is used to evaluate and to identify the lessons learned

Step 10: Conclusions

Conclusions will be drawn:

- if incomplete data: return to step 5
- proposed actions and/or recommendations
- dissemination of good practices

Step 11: Archiving data

- Research institute takes charge of the collected data
- Data will be digitally archived
- Only CDR coordinator is authorized to access the data
- Archived data may be used for monitoring and evaluation purposes

SERRAFIM 2009-2012

- Partners
  - University of Münster, Institute of Legal Medicine
  - TNO, Quality of Life
  - University of Twente, Health Technology and Services Research
- Collaboration:
  - Dutch Perinatal Audit Foundation/ UMC Groningen
  - KNMG: NODO-implementation committee
  - Dutch Cot Death Foundation
  - Forensic Medical Association Twente (FOMAT)

Funding

- INTERREG
- Ministry for Youth and Families
- Land NRW, Land Niedersachsen,
- University of Münster, University of Twente
- TNO Quality of Life
- Menzis Health Insurance
- MKB Netherlands
- Foundation ‘Kinderpostzegels’ Netherlands
- Kassenärzliche Vereinigung NRW
- Lionsclub Hamaland

Thanks for your attention

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