

Getting started: Setting up a research project in paediatric palliative care

Manya Hendriks, PhD, Department of Neonatology, University Hospital Zurich,
University of Zurich, Switzerland.

Karin Zimmermann, PhD RN, University Children's Hospital Zurich; Department
Public Health – Nursing Science, University Basel

Closing symposium on the SAMS funding program
Research in Palliative Care 2014-2018
Thursday, 21. November 2019, Bern



Vulnerable research populations

“Research projects involving particularly vulnerable participants are only ethically justifiable and permissible if the principle of subsidiarity is respected: particularly vulnerable persons may only be involved in a research project if equivalent findings cannot be obtained by other means.”

Thus, for example, a research project involving children or families of a critically ill (unborn) baby may only be carried out if, for scientific reasons, the knowledge sought can only be obtained by this research population.

Research with human subjects. *A manual for practitioners.*
Bern: Swiss Academy for Medical Sciences (SAMS), 2015.

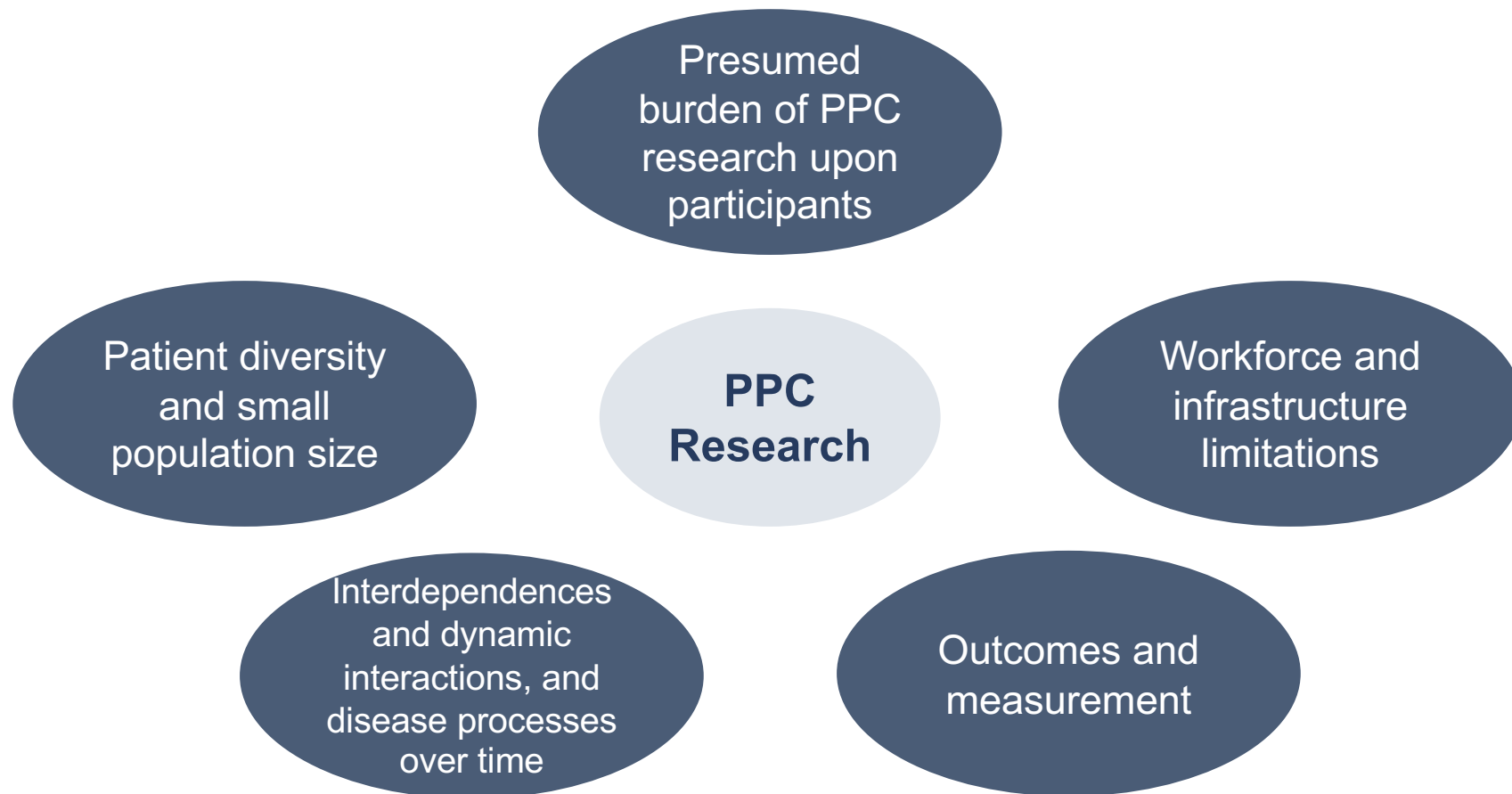


Finding the Balance



FIG. 1. Conceptual model. Conducting pediatric palliative care research requires a delicate balance of weighing the burdens and benefits in this vulnerable population. Word size and color correlate with frequency of finding.

Challenges for Paediatric Palliative Care Research

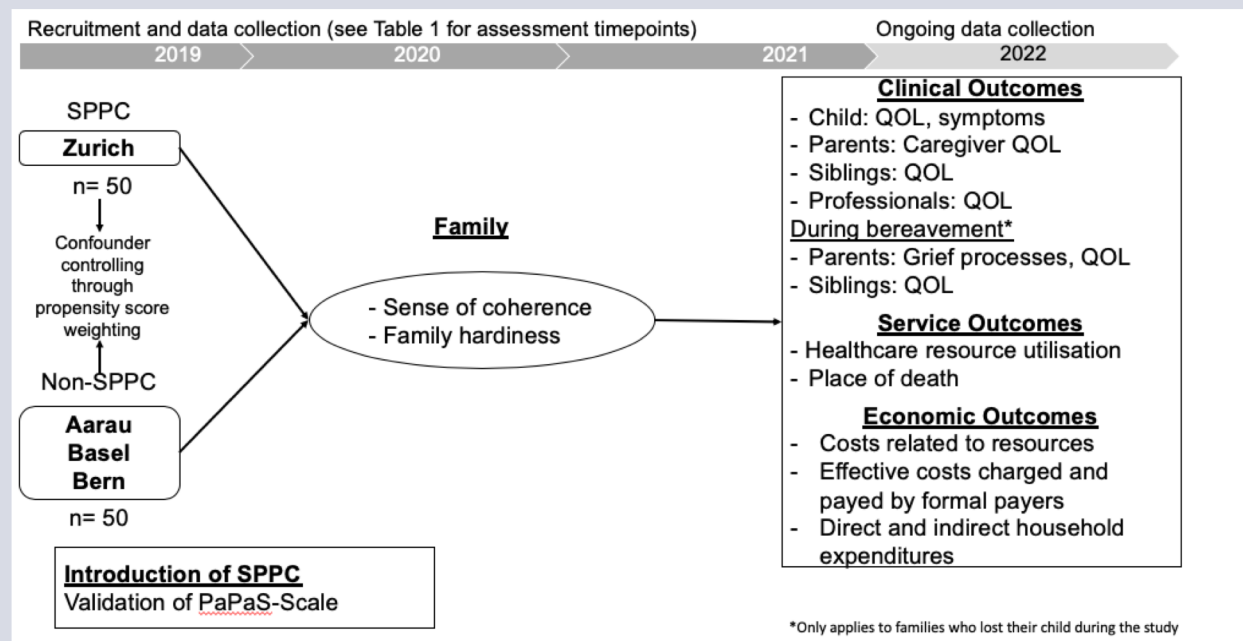


Feudtner et al. (2019). Challenges and Priorities for Pediatric Palliative Care Research in the United States and Similar Practice Settings: Report from a Pediatric Palliative Care Research Network Workshop. *Journal of Pain and Symptom Management*. doi: 10.1016/j.jpainsymman.2019.08.011

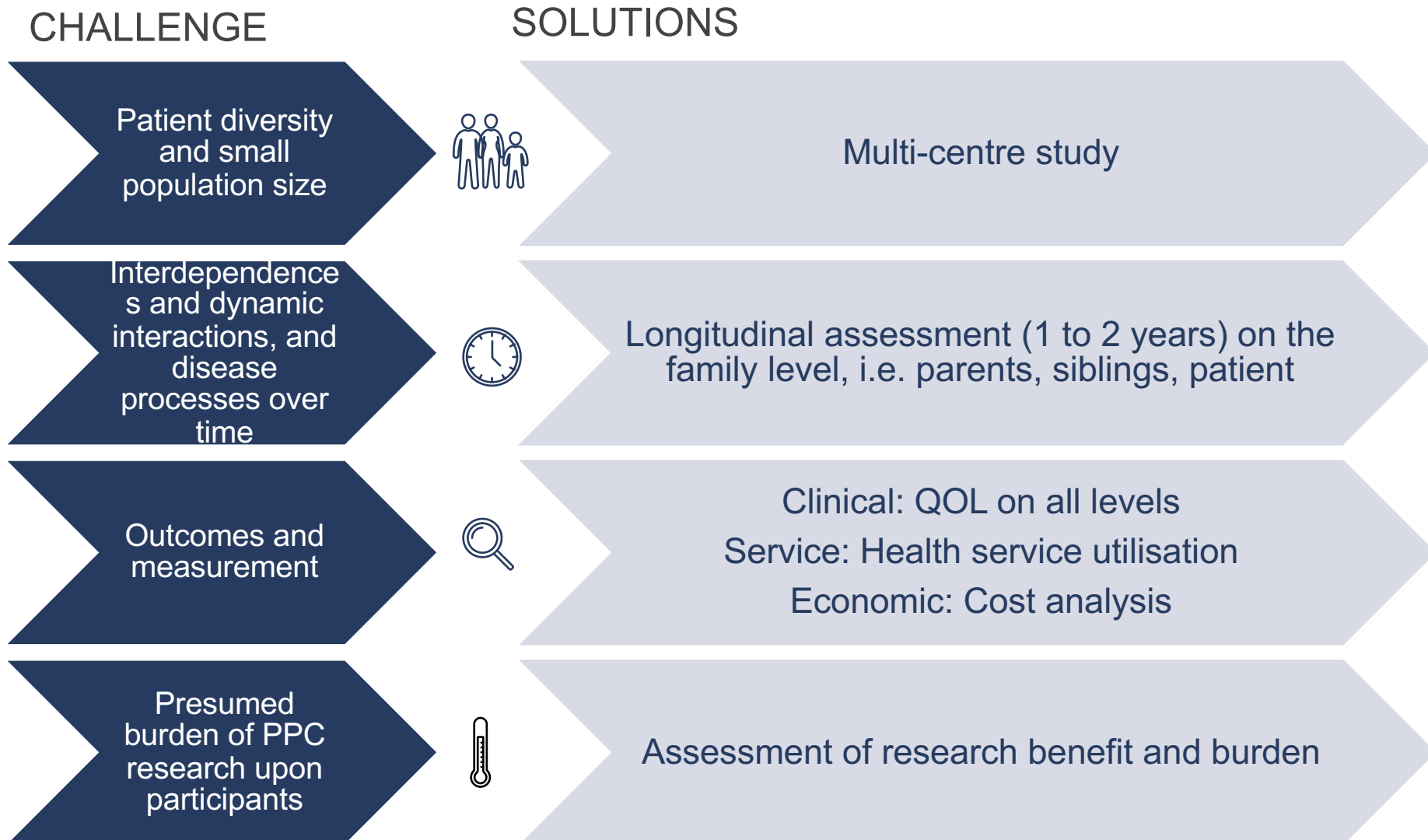
SPhAERA: Specialised Paediatric Palliative CaRe: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings

This study's overall target is to evaluate the effectiveness of SPPC and to report on its potential to improve patient-, family-, health professional-, and healthcare-related outcomes.

Further objectives are to determine whether the provision of SPPC reduces the utilization of healthcare resources and direct and indirect health-related costs for families.

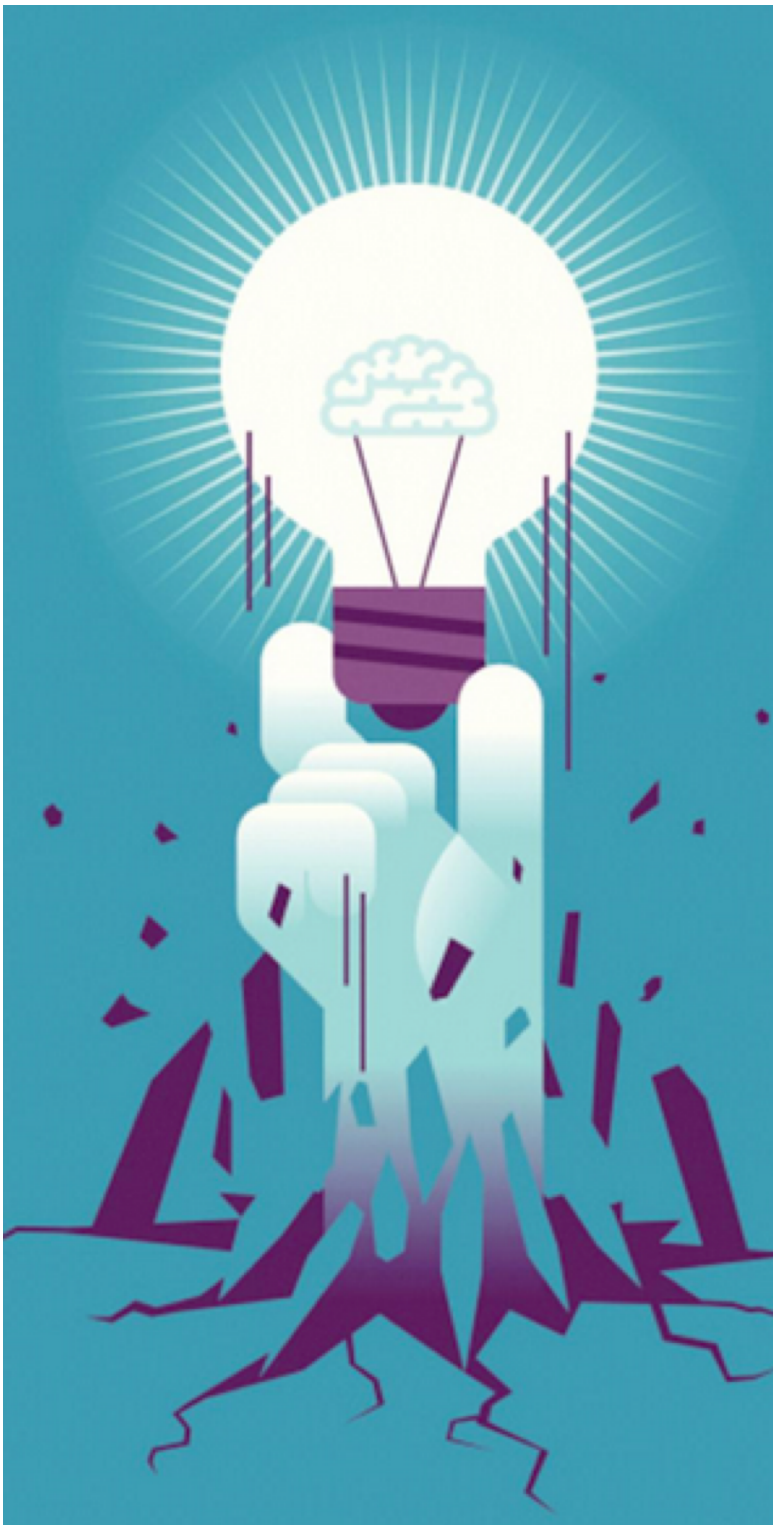


Challenges and Efforts: SPhAERA study



Impact of the SPhAERA study

- Expand current knowledge
- Relevant outcome data on the family, professional, and health system level
- Facilitate further development and sustainability of PPC in Switzerland
- Improve quality of care for children with life-limiting conditions and their families internationally



FamKom : A Mixed Methods Study on Perinatal Palliative Care Services in Switzerland

The goal of this nationwide study is:

**Part 1:
Survey**

to assess perinatal palliative care practices of healthcare professionals working in Swiss level III neonatal intensive care units (NICUs) (N=428)

**Part 2:
Audio-
recording**

to prospectively analyze perinatal PC consultations (i.e. HCPs-parent communication) in clinical practice (N=45)

**Part 3: Focus
groups**

to develop communication strategies with HCPs for perinatal palliative care (N=16)



Challenges and Efforts: *FamKom Study*

CHALLENGE

SOLUTIONS

Patient diversity
and small
population size



Multi-centre study; Longer data collection
process

Workforce and
infrastructure



Centre-specific adaptations and
Multidisciplinary approach

Presumed
burden of PPC
research upon
participants



Close collaboration with clinicians as clinical
gatekeepers

Impact of the FamKom Study

Potential to lead to:

- Better understanding of palliative care consultations
 - quantitative aspects of communication
 - qualitative aspects of the interactions
- Avoiding problems with recall bias
- Strengthening nationwide collaborations of perinatal palliative care
- Initiating a national approach to perinatal palliative care situations
- Designing evidence based educational tools for communicating with families in perinatal palliative care settings

Conclusions



Research in Paediatric Palliative Care needs to think outside the beaten and narrow path of conventional clinical research:

- Ethical considerations
- Interprofessional collaboration
- Research infrastructure und groups
- Advanced research designs, e.g.,:
 - comparative effectiveness research,
 - mixed-methods,
 - implementation science



*Thank you for your
attention!*



Project Team:

Dr. Karin Zimmerman, PhD RN
PD Dr. med. Eva Bergsträsser
Prof. Dr. Michael Simon, PhD RN
Prof. Dr. Günther Fink
Anne-Kathrin Gerber, MA Health Sciences
Stefan Mitterer, MPhil Health Economics

Contact:

karin.zimmermann@kispi.uzh.ch

Project Team:

Dr. sc. med. Manya Hendriks, PhD
Dr. med. Deborah Gubler, PhD
Prof. Dr. med. Jean-Claude Fauchère
Antonio Boan-Pion, MSc

Contact:

manya.hendriks@usz.ch



“Forschung in Palliative Care”



ssp sgp

SWISS SOCIETY OF PAEDIATRICS
Ihre Ärztinnen und Ärzte für Kinder und Jugendliche
Les médecins de vos enfants et adolescents
I medici dei vostri bambini e adolescenti

SWISS
PEDNET

Swiss Research Network of
Clinical Pediatric Hubs

Olga
Mayenfisch
Stiftung

USZ neonatal
department



University of
Zurich^{uzh}