Insights and priorities from clinical practice connecting with research

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@josephcmanning
#PedsICU #PICSp

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Disclosure

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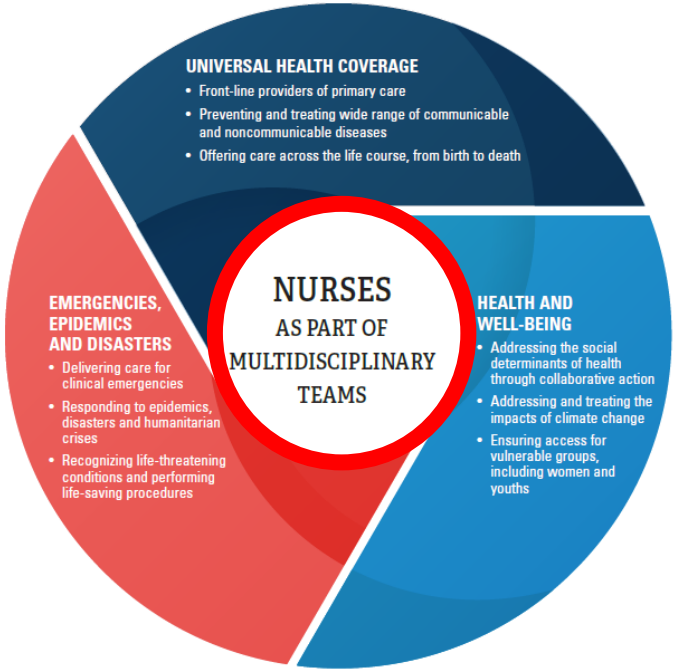
Overview

- Global context of nursing and science
- Insights and priorities
- 12+ years - programme of research
- Reflections in connecting research with clinical practice

The global nurse

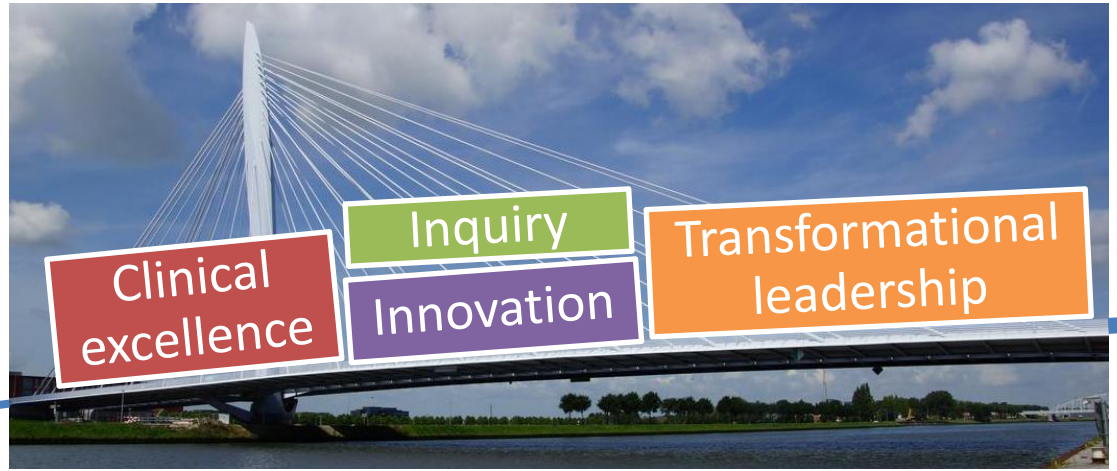


- WHO triple billion target
- Nurses a pivotal partner of the multidisciplinary team
- Their role in future healthcare landscape

State of the world's nursing 2020: investing in education, jobs and leadership. Geneva: World Health Organization; 2020.

Bridging clinical practice with research

Clinical insights and priorities



Research with utility and impact

@josephcmanning #PedsICU #PICSp

The shifting focus

70s: 1st revolution: a well-organized approach, not merely individual excellence, could save the lives of the very sick.

90s: 2nd revolution: a well-organized approach could provide a good death (or dying process) to those that can't be saved.

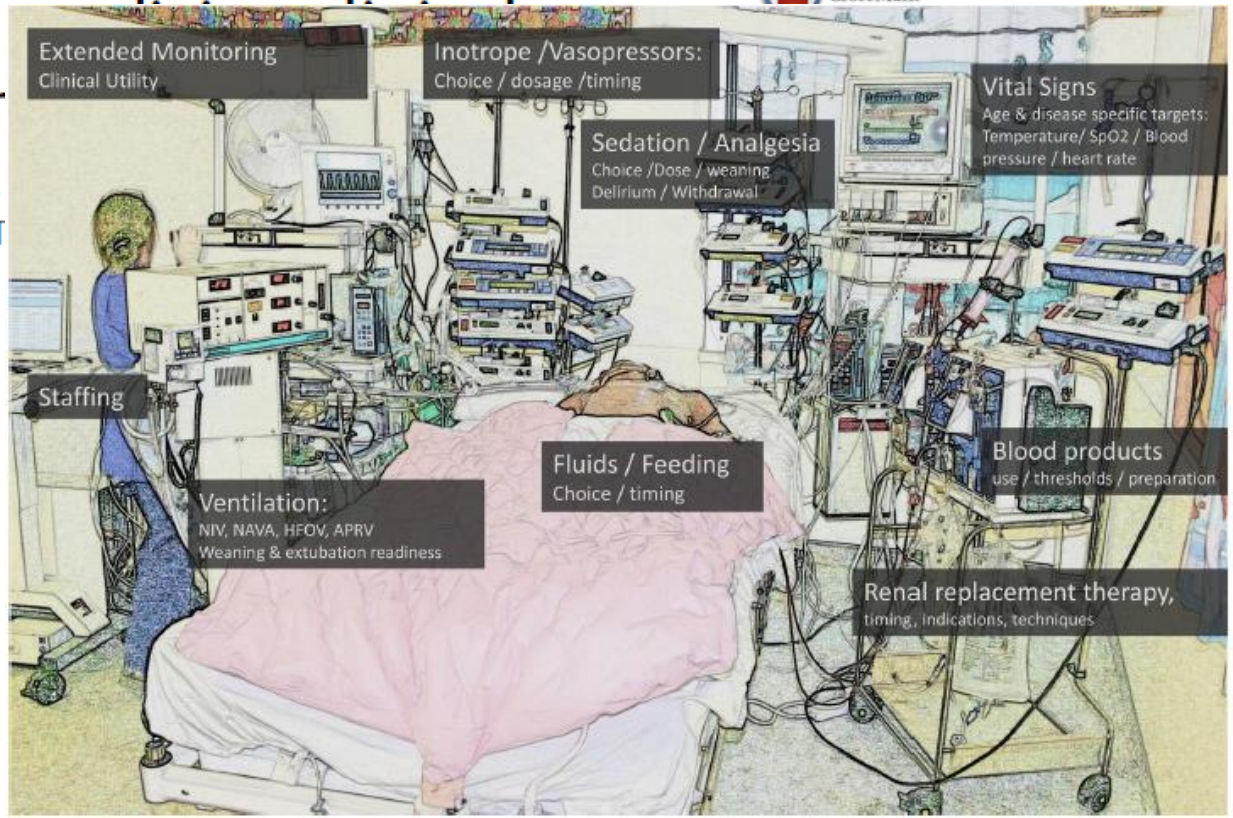
Today: 3rd revolution: a well-organized approach can help those who survive critical illness live full new lives; lives not the same as they were before, but also not necessarily less.

Iwashyna & Speelmon, AJRCCM 2016;194(7): 782-783.

The intensive care research agenda ir

Mark J. Peters[1], Andrew Argent[2], Marino
Douglas Willson[7], Pierre Tissières[8], Marisa T

Intensive Care Med (2017) 43:1210–1224
DOI 10.1007/s00134-017-4729-9



AMERICAN THORACIC SOCIETY DOCUMENTS

Nursing Research Priorities in Critical Care, Pulmonary, and International Delphi Survey of Nurses, Patients, and Caregive

An Official American Thoracic Society Workshop Report

Maureen George, Carme Hernandez, Sheree Smith, Georgia Narsavage, Mary C. Kapella, Margaretann
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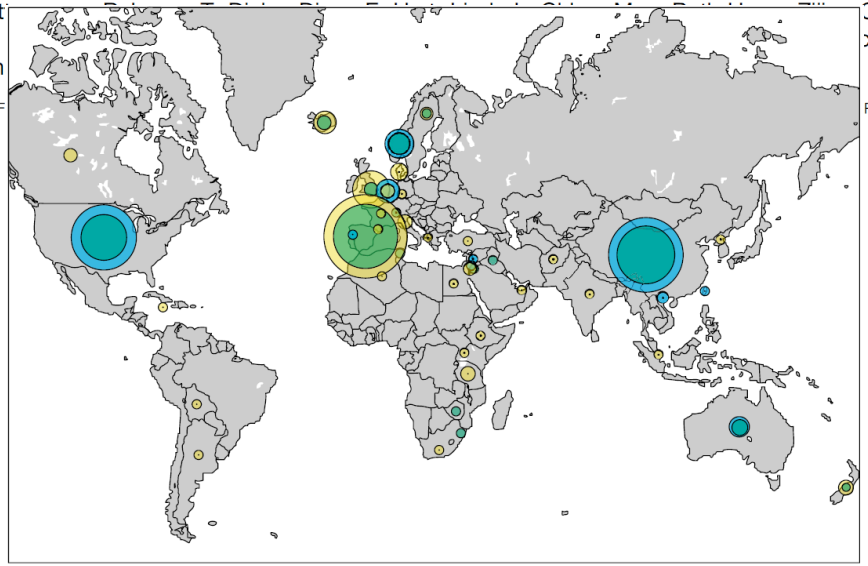

Table 3. Nursing research priorities in critical care—final items endorsed by all nurses, patients, and caregivers

Patient-reported outcomes

1. Development and evaluation of interventions to reduce the incidence and/or duration of delirium
2. Development and evaluation of assessment tools to identify dyspnea (breathlessness/ shortness of breath)
3. Development and evaluation of interventions to manage dyspnea (breathlessness/ shortness of breath)
4. Promotion of routine assessment of common symptoms, such as anxiety, thirst, breathlessness/dyspnea, and fatigue
5. Development and evaluation of nonpharmacologic interventions to manage anxiety
6. Development and evaluation of nonpharmacologic interventions to manage dyspnea (breathlessness/ shortness of breath)
7. Describe relationships or clusters among critically ill patients' symptoms (e.g., dyspnea, anxiety, pain, etc.)
8. Describe the relationship between patient symptoms or experiences during critical illness and patient outcomes and recovery
9. Description of fear (feeling scared) during critical illness
10. Development and testing of nonpharmacologic interventions to manage pain or discomfort
11. Evaluation of assessment tools to measure sleep during critical illness
12. Evaluation of fatigue during critical illness
13. Development and evaluation of nonpharmacologic interventions to improve sleep during critical illness
14. Evaluation and description of emotional responses during critical illness such as anger, grief, or sadness
15. Development of a pre-hospital discharge or pre-ICU discharge intervention or tool to identify potential challenges during recovery (e.g., decreased physical, psychosocial, or cognitive function)
16. Identification and testing of interventions during acute hospitalization/ICU to improve recovery from critical illness (e.g., improve physical, psychosocial, cognitive, or quality-of-life outcomes)
17. Identification and testing of interventions for after the ICU to improve recovery from critical illness (e.g., improve physical, psychosocial, cognitive, or quality-of-life outcomes)
18. Evaluation and description of sleep disturbances during recovery from critical illness
19. Evaluation and description of fatigue during recovery from critical illness

Patient-reported experiences

1. Integration, into routine care, of interventions to enhance patient communication during mechanical ventilation
2. Evaluation of patient outcomes related to communication ability during mechanical ventilation
3. Identification and evaluation of communication/advocacy interventions to promote patient/family engagement and participation in decision-making
4. Description and impact of patients' feelings such as depersonalization, uncertainty, and vulnerability experienced during critical illness

- ✓ Role
- ✓ Population
- ✓ ICU/PICU/NICU
- ✓ Organisation
- ✓ Health System
- ✓ Country

Priorities from my practice

The SCETCH study

Open Access Protocol

BMJ Open

BMJ Open 2014;**4**:e004230. doi:10.1136/bmjopen-2013-004230

Protocol for a longitudinal qualitative study: survivors of childhood critical illness exploring long-term psychosocial well-being and needs—The SCETCH Project

Joseph C Manning,[1,2] Pippa Hemingway,[1] Sarah A Redsell[3]

- **Single site, prospective, longitudinal qualitative study**
- **'Tool box' of methods – elicit survivor narratives and that of 'significant others'**

Article

JCHC

Stories of survival: Children's narratives of psychosocial well-being following paediatric critical illness or injury

Journal of Child Health Care
1–15
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1367493517717078
journals.sagepub.com/home/chc

SAGE

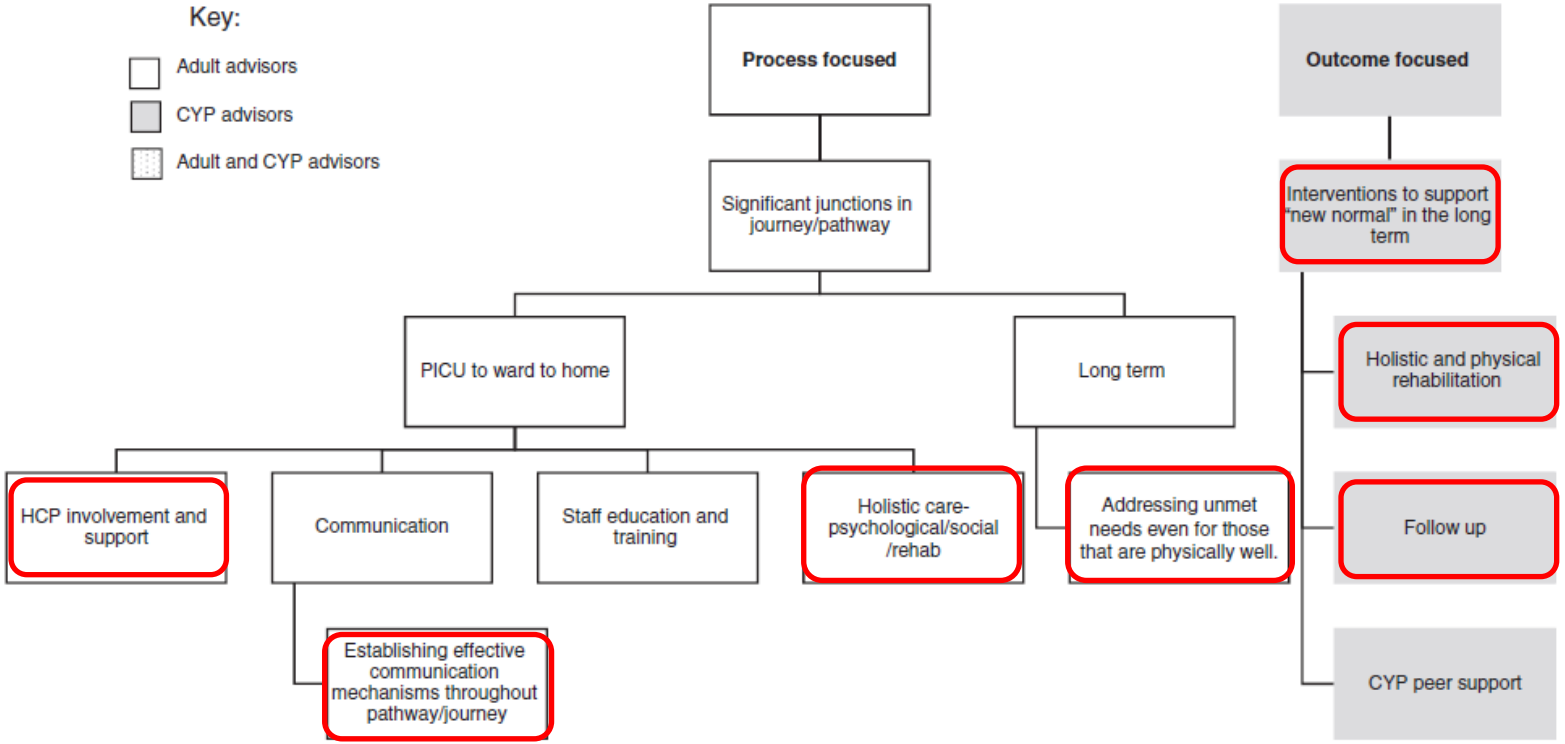
Joseph C Manning[1], Pippa Hemingway[1], and Sarah A Redsell[2]

- Longitudinal accounts (6-20 months post-PICU)
- Heterogeneous group of survivors
- Biographies important in governing well-being
- Outstanding needs: Traumas, readjustment; psychological and social

Linking back to practice

- PICU Survivors
- Siblings
- Parents and careers

- Service commissioners
- Health professionals
- Researchers



Manning et al (2017)

Linking back to practice standards

Quality Standards

- Rehabilitation goals
- Transfer from critical care
- Information on discharge from hospital
- Follow-up after critical care discharge

Received: 10 January 2020 | Revised: 28 March 2020 | Accepted: 31 March 2020
DOI: 10.1111/nicc.12510

EVALUATION

BACCN Nursing in Critical Care WILEY

Paediatric intensive care follow-up provision in the United Kingdom and Republic of Ireland

Joseph C. Manning RN, PhD[1,2] | Barnaby R. Scholefield MBBS, PhD[3,4] | Emma Popejoy RN, PhD[1,2] | Elizabeth Dodds RN, MNursSci (Hons)[5] | Jos M. Latour RN, PhD[6,7]

- Cross-sectional survey
- 22/28 PICUs in UK and Republic of Ireland.

Results:

- Lack of:
  - guidelines and protocols
  - criteria to identify those requiring aftercare
- Variation in the delivery, content and format of early aftercare
- Paucity in provision of late aftercare

Future research:

- Comprehensively map outcomes
- Understand needs
- Interventions – types and who to target

A force between practice and science





Conceptualizing Post Intensive Care Syndrome in Children—The PICS-p Framework

Joseph C. Manning, RN, PhD[1]; Neethi P. Pinto, MD, MS[2]; Janet E. Rennick, RN, PhD[3,4,5]; Gillian Colville, MPhil, CPsychol[6]; Martha A. Q. Curley, RN, PhD[7,8]

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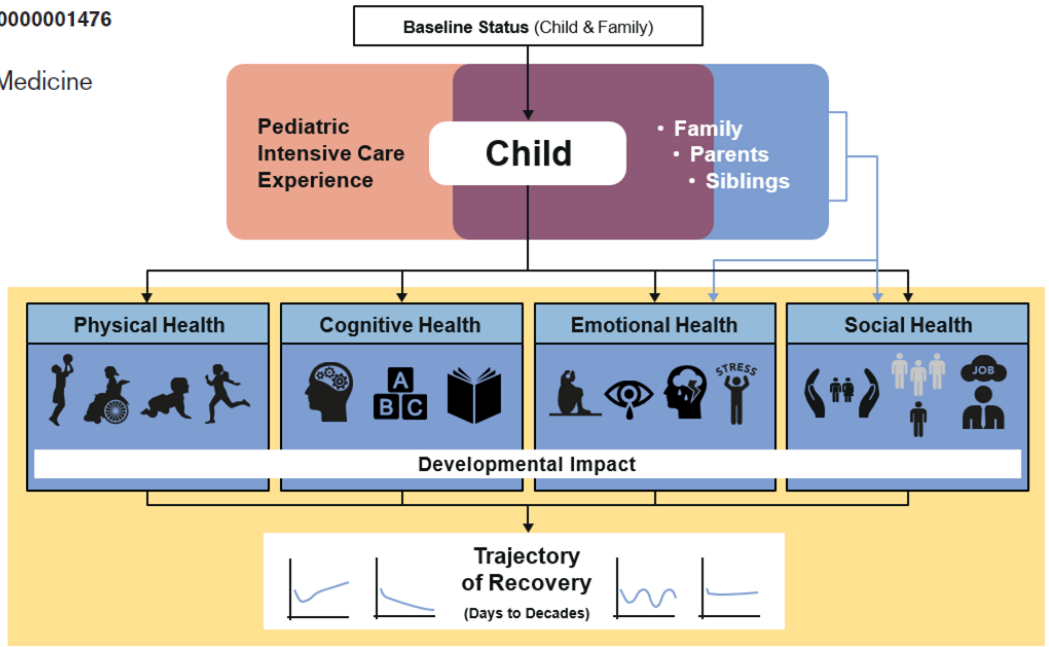
DOI: 10.1097/PCC.0000000000001476

Pediatric Critical Care Medicine

Antecedence



Varied patient characteristics

- Status (medical history; functional; SES)

Childhood- a dynamic state

Developmental impact

Family- an interdependent unit

Manning et al. 2018 Paediatric Critical care Medicine

Conceptualizing Post Intensive Care Syndrome in Children—The PICS-p Framework

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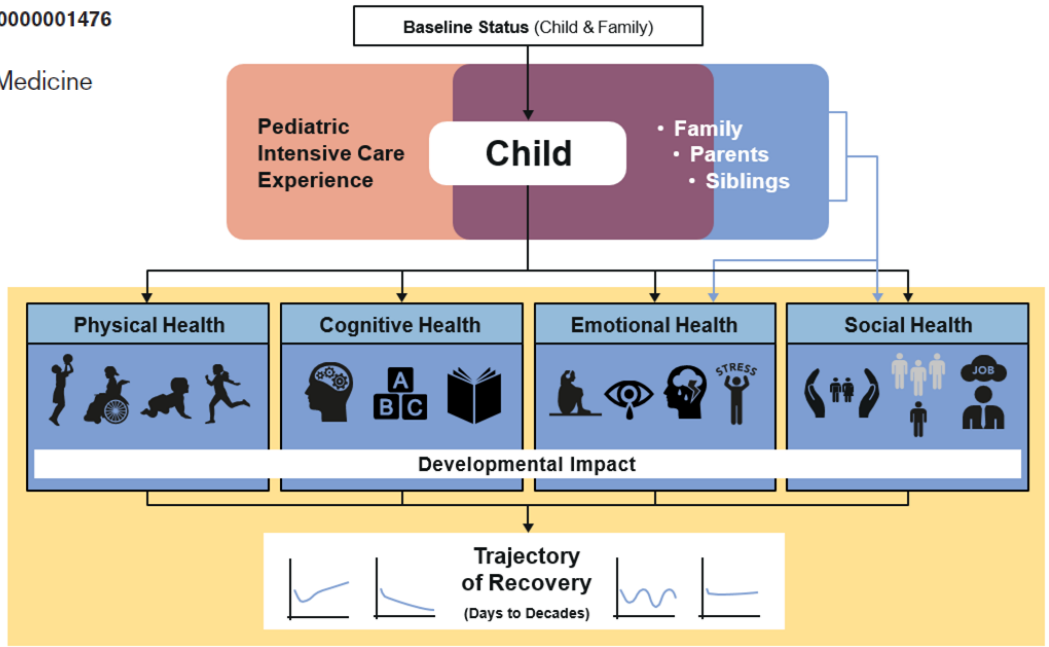
Pediatric Critical Care Medicine



Antecedence

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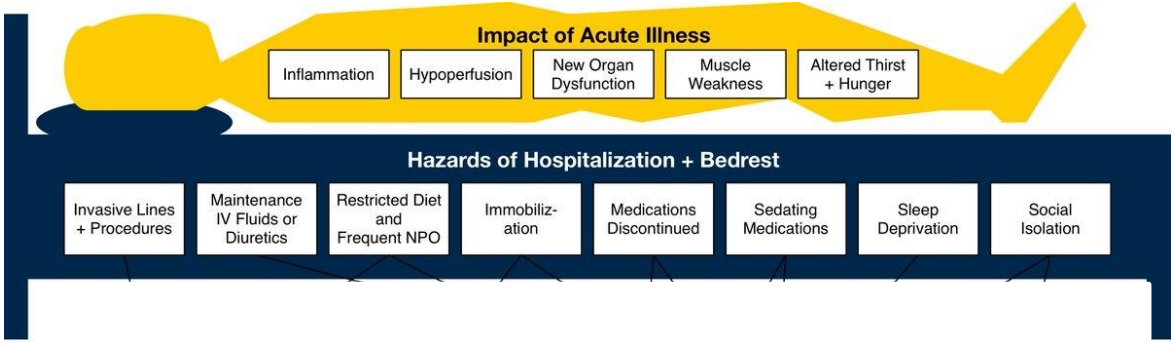
Phenomena



Source: Mikkelsen & Iwashyna (2018) *Oxford Textbook of Medicine*, 6th ed.
Inspired by Creditor (1993) *Ann Int Med*

Parental stressors :

- PICU environment
- Changes to parental role / family functioning
- Acuity / uncertainty of outcome

Parental Needs:

- Recognized as team member
- Participating in the decision-making
- Access to detailed, well-timed, and honest information
- Gender differences regarding parent needs

Siblings:

- Changes in parental behaviour
- Care by a substitute caregiver
- Repetitive contact with distressing content
- Age-inappropriate adult responsibilities for siblings

Conceptualizing Post Intensive Care Syndrome in Children—The PICS-p Framework

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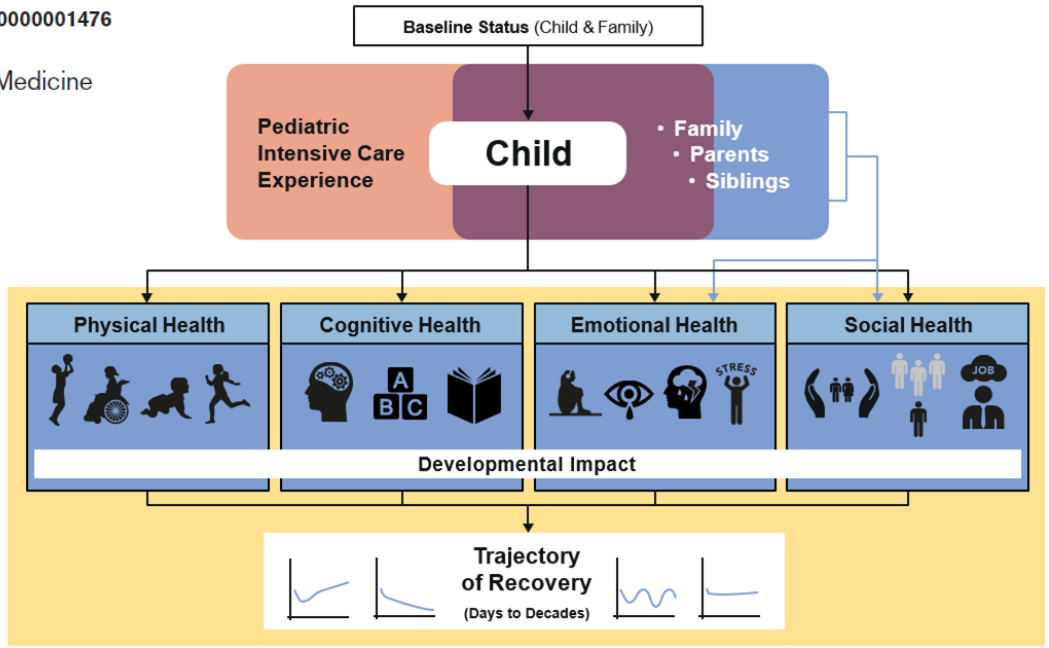

Antecedence

Phenomena

Outcome

- Motor dysfunction
- Breathing problems
- Feeding problems
- Posttraumatic stress
- Sadness and depression
- Difficulty sleeping
- Behaviour changes
- Learning and attention

Child ⇄ **Parents / Siblings**

- Anxiety and Depression
- Posttraumatic stress
- Additional caregiving roles
- Changes to social status

Functional disability: ≤67% ● Impaired HRQoL: ≤75% ● Impaired emotional health: ≤25%

Limitations

☹ Specific medical conditions

☹ Specific age groups

☹ Follow up at one time point

☹ No consensus on outcomes measured

≠

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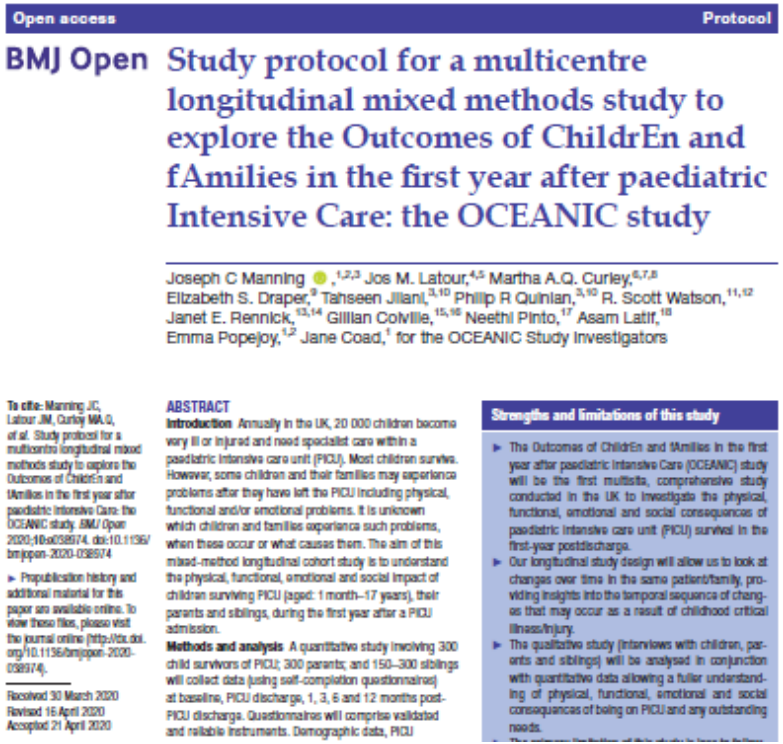
Nottingham Children's Hospital
Nottingham University Hospital NHS Trust
The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

The OCEANIC Study

A multi-centre longitudinal mixed-methods study to explore the Outcomes of ChildrEn and fAmilies iN the first-year after paediatric Intensive Care discharge

Co-Investigators
Professor Jane Coad - Professor of Children and Families Nursing, University of Nottingham
Professor Jos Latour - Professor of Clinical Nursing, Plymouth University
Professor Elizabeth Draper - Professor of Neonatal and Paediatric Epidemiology, University of Leicester
Dr Philip Quinlan – Associate Director of HDR Midlands and Head of the Digital Research Service, University of Nottingham
Professor Martha Curley – Ruth M. Colket Endowed Chair in Pediatric Nursing, Children's Hospital of Philadelphia and Professor of Anaesthesia and Critical Care Medicine, University of Pennsylvania

@josephcmanning #PedsICU #PICSp



Open access Protocol

BMJ Open

Study protocol for a multicentre longitudinal mixed methods study to explore the Outcomes of ChildrEn and fAmilies in the first year after paediatric Intensive Care: the OCEANIC study

Joseph C Manning ,[1,2,3] Jos M. Latour,[4,5] Martha A.Q. Curley,[6,7,8] Elizabeth S. Draper,[9] Tahseen Jilani,[3,10] Philip R Quinlan,[3,10] R. Scott Watson,[11,12] Janet E. Rennick,[13,14] Gillian Colville,[15,16] Neethi Pinto,[17] Asam Latif,[18] Emma Popejoy,[1,2] Jane Coad,[1] for the OCEANIC Study Investigators

To cite: Manning JC, Latour JM, Curley MAQ, *et al*. Study protocol for a multicentre longitudinal mixed methods study to explore the Outcomes of ChildrEn and fAmilies in the first year after paediatric Intensive Care: the OCEANIC study. *BMJ Open* 2020;10:e038974. doi:10.1136/bmjopen-2020-038974

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2020-038974).

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Revised 16 April 2020
Accepted 21 April 2020

ABSTRACT

Introduction Annually in the UK, 20 000 children become very ill or injured and need specialist care within a paediatric intensive care unit (PICU). Most children survive. However, some children and their families may experience problems after they have left the PICU including physical, functional and/or emotional problems. It is unknown which children and families experience such problems, when these occur or what causes them. The aim of this mixed-method longitudinal cohort study is to understand the physical, functional, emotional and social impact of children surviving PICU (aged: 1 month–17 years), their parents and siblings, during the first year after a PICU admission.

Methods and analysis A quantitative study involving 300 child survivors of PICU; 300 parents; and 150–300 siblings will collect data (using self-completion questionnaires) at baseline, PICU discharge, 1, 3, 6 and 12 months post-PICU discharge. Questionnaires will comprise validated and reliable instruments. Demographic data, PICU

Strengths and limitations of this study

- The Outcomes of ChildrEn and fAmilies in the first year after paediatric Intensive Care (OCEANIC) study will be the first multisite, comprehensive study conducted in the UK to investigate the physical, functional, emotional and social consequences of paediatric intensive care unit (PICU) survival in the first-year postdischarge.
- Our longitudinal study design will allow us to look at changes over time in the same patient/family, providing insights into the temporal sequence of changes that may occur as a result of childhood critical illness/injury.
- The qualitative study (interviews with children, parents and siblings) will be analysed in conjunction with quantitative data allowing a fuller understanding of physical, functional, emotional and social consequences of being on PICU and any outstanding needs.

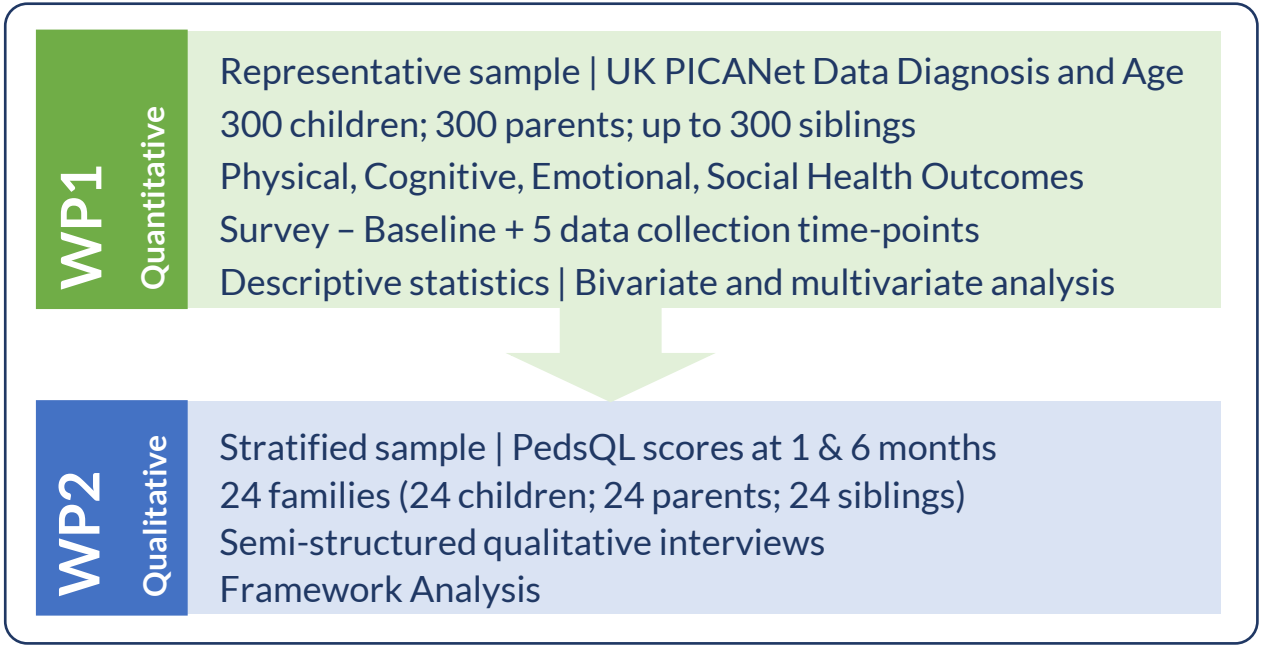
RQ: What are the physical, cognitive, emotional, and social health outcomes, and their trajectories, of children and their family members in first year after-PICU discharge?

Objectives:

1. To describe trajectory of recovery in children post-PICU discharge.
2. To determine the baseline and PICU factors associated with impaired outcomes.
3. To explore the longitudinal emotional and social health outcomes of parents and siblings.
4. To ascertain the care and support needs of children and their parents and siblings.

The OCEANIC Study

- **A multi-centre longitudinal mixed-methods design**
- **Two linked work-packages**

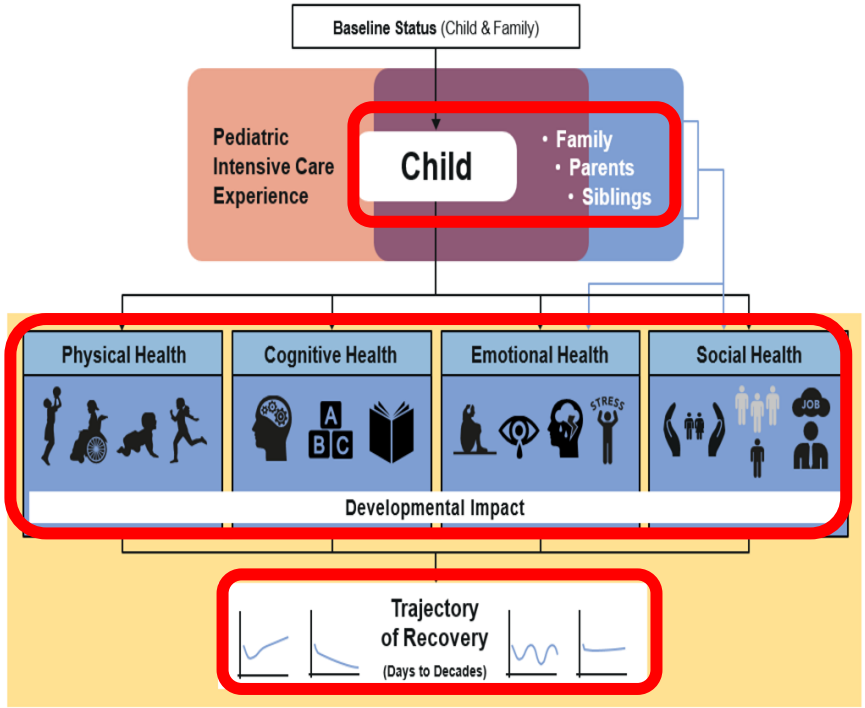


Generalisable results:
- Those at risk
- When morbidities manifest
- Any modifiable factors

Transferable findings:
- Caring roles
- Needs

Develop interventions

Direct future research in field



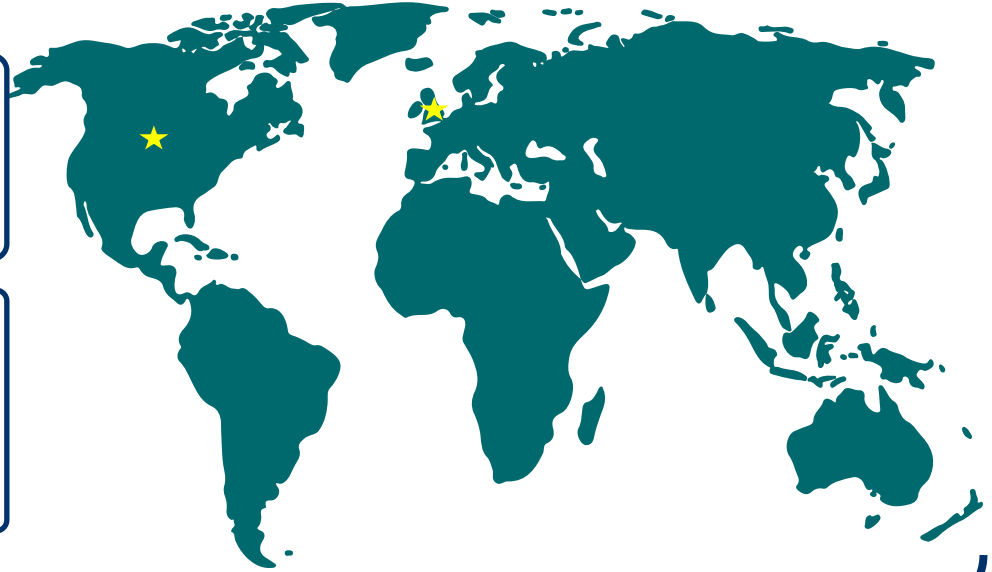
Manning et al (2018) Conceptualising Post-Intensive Care Syndrome in Pediatrics: The PICS-p framework. ***Paediatric Critical Care Medicine****. 2018 Apr;19(4):298-300.*

The OCEANIC Study

UK, Funder: NIHR

PICS-p Longitudinal Cohort Study

US, Funder: NIH



Intervention development and testing

“In 1994 my seven year old son spent three weeks in PICU where he was diagnosed with Guillain Barre syndrome.

The experience had a profound impact on my son and my daughters aged 4 and 18 months . My partner and I stayed at the hospital with our daughters for two and a half weeks keeping watch at his bedside 24 hours a day.

Over the years I have searched for material that would support us in working with the ongoing challenges, both emotional and psychological, that we each experienced during hospitalisation and on returning home.

We felt very alone in our attempts to make sense of and understand the experience.”

Deborah (Mother), *January 2021*

Connecting research with practice through…

….critical inquiry

- **Reflective reasoning**
  - Inquiry
  - Logical reasoning

- **Application of standards**
- **Impact ongoing changes to practice**
- **Safe and ethical care**

Educating the Future Nurse – a paper for discussion. London: Council of Deans of Health. 2016

Knowledge development, technology and questions of nursing ethics

Nursing Ethics
2020, Vol. 27(1) 77–87
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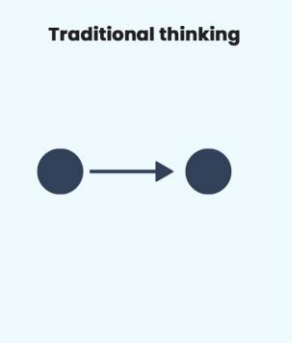
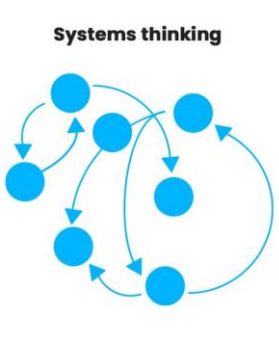
Anne Griswold Peirce, Suzanne Elie, Annie George, Mariya Gold, Kim O'Hara and Wendella Rose-Facey
Adelphi University, USA

Era of 'big data' and machine learning

Critical inquiry capability and skills

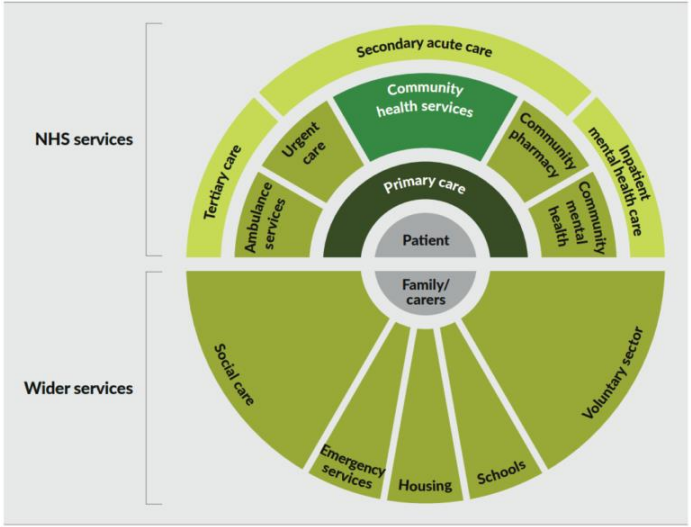
….shift to systems thinking



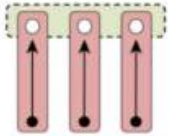


Impact across the system:

- Transformational leadership
- Knowledge exchange
- Practice expertise

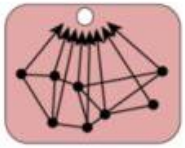


….effective collaboration



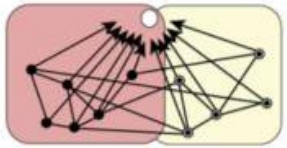
Multidisciplinary

- Multiple disciplines
- Multiple disciplinary goal setting under one thematic umbrella



Interdisciplinary

- Crosses disciplinary boundaries
- Development of integrated knowledge

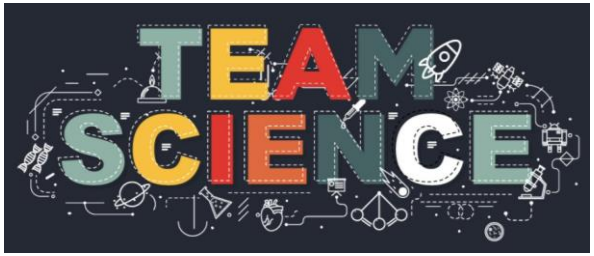


Convergence

- Crosses disciplinary and sectorial boundaries
- Common goal setting
- Develops integrated knowledge for science and society
- Creates new paradigms

Stakeholder Participants
Discipline
Goal, Shared Knowledge
Academic Knowledge
Thematic Umbrella
Conventional Knowledge

Adapted from Wright Morton, L., S. D. Eigenbrode, and T. A. Martin. 2015. Architectures of adaptive integration in large collaborative projects. *Ecology and Society* 20(4):5.



Expertise and insight:

- **Sectors**
- **Disciplines**
- **Clinical**
- **Methodological**
- **Experiential**

Priorities from my practice


TEDx Cincinnati

Conclusion

- Science needs to align to patients and nursing priorities = impactful
- Developing and embedding research culture is every nurses business.
- Knowledge mobilisation (e.g. EBP) → Knowledge generation
- Without [nursing] science there is no advancement to our profession, field/specialty, or clinical practice.

“Do not compromise”

- Steve Jobs

….And connect research to your practice

Thank you

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@josephcmanning #PedsICU #PICSp

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