

# The PIPPIN Project; Paediatric Intensive care Public Patient INvolvement, where we started...

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IRNN 11<sup>th</sup> Annual National Conference 8<sup>th</sup> November 2018



Benefits of involving patients, families and service users in developing, implementing and evaluating healthcare services and research

- Enhanced health outcomes
- Increased satisfaction with services
- Better adherence to treatment

• DoH (2010), Menzies et al (2016)



## Acknowledgements:

Hazel Ann Smith, Research Coordinator for the Paediatric Intensive Care Unit, Our Lady's Children's Hospital, Crumlin.



Sarah Bowman, Director of Strategic Engagement, HRB-TCD Ignite Programme Director, Trinity College Dublin, Ireland.

Veronica Lambert; Associate Professor Children's Nursing, HRB PPI Ignite Lead, School of Nursing and Human Sciences, DCU



Mary Costello; Clinical Research Project Manager, National Children's Research Centre, Crumlin, Dublin.

Thilo Kroll; Professor of Health Systems Management, HRB PPI Ignite Lead, Associate Dean for Research, Innovation and Impact, UCD.



# UN Convention on the Rights of the Child

These are the 4 Guiding Principles of the UN Convention on the Rights of the Child. Each of the articles in the Convention is informed by these principles.

**1 Non-discrimination**  
treat everyone fairly and with respect

**2 Right to life, survival, & development**  
children & youth have a right to the basic things to live, survive, & develop

**3 Best interests of children & youth**  
always ask yourself:  
*"is the decision I'm making good for kids?"*

**4 Respect the views of children & youth**  
children & youth need to participate and have their views considered when decisions are being made that affect them

[everychild.ca](http://everychild.ca)



# World Health Organization

UN and WHO enshrine the views of children on issues affecting them. RECs and funding bodies now request evidence of engagement.

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Menzies *et al. Research Involvement and Engagement* (2016) 2:32  
DOI 10.1186/s40900-016-0046-7

Research Involvement  
and Engagement

REVIEW ARTICLE

Open Access



# Patient and public involvement in Paediatric Intensive Care research: considerations, challenges and facilitating factors

J. C. Menzies<sup>1\*</sup>, K. P. Morris<sup>1</sup>, H. P. Duncan<sup>1</sup> and J. F. Marriott<sup>2</sup>




Little evidence to show PPI in PICU setting is occurring

## PPI in Paediatric Intensive Care Context

- Conduct of research challenging in this setting
- Stressful, busy often noisy environment
- Inpatient stay fraught with anxiety
- Views of CYP and parents/carers essential in PICU research design
- No measurement of impact of PPI in PICU research
- Need to enhance understanding of effective PPI in PICU



# Survived so what? Identifying priorities for research with children and families post-paediatric intensive care unit

Joseph C Manning , Pippa Hemingway and Sarah A Redsell

## **ABSTRACT**

The involvement of patients and the public in the development, implementation and evaluation of health care services and research is recognized to have tangible benefits to effectiveness and credibility. However, despite >96% of children and young people surviving critical illness or injury, there is a paucity of published reports demonstrating contribution to informing the priorities for aftercare services and outcomes research. We aimed to identify the service and research priorities for Paediatric Intensive Care Units with children and young people, their families and other stakeholders. We conducted a face-to-face, multiple-stakeholder consultation event, held in the Midlands (UK),

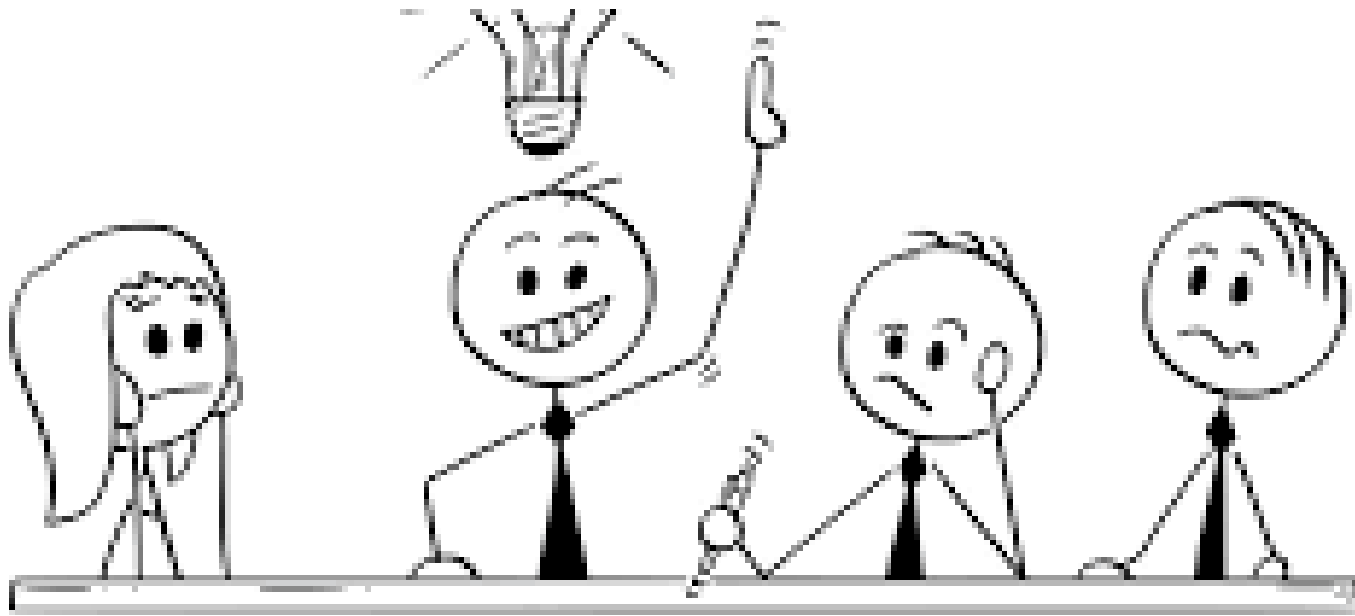
# Parents' and young people's involvement in designing a trial of ventilator weaning

Lyvonne N. Tume, Jenny Preston and Bronagh Blackwood

## **ABSTRACT**

Consulting with users is considered best practice and is highly recommended in designing new trials. As part of our feasibility work, we undertook a consultation exercise with parents, ex-patients and young people prior to designing a trial of protocol-based ventilator weaning. Our aims were to (1) ascertain views on the relevance and importance of the trial; (2) determine the important parent/patient outcome measures; and (3) ascertain views on informed consent in a cluster randomized controlled trial. We conducted audio-recorded face-to-face, telephone and focus group interviews with parents and young people. Data were content analysed to generate information to address our specific consultation objectives. The setting was the north-western region of England. A total of 16 participants were interviewed: 7 parents of paediatric intensive





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Interdisciplinary, multi-site  
working group

- To develop the Terms of Reference for PIPPIN
- To develop an action plan to implement the activities planned with PIPPIN
- To create a monitoring and evaluation protocol to determine uptake, experiences and efficacy of PIPPIN

A HOW TO  
GUIDE

# ENGAGED RESEARCH PLANNING FOR IMPACT

SOCIETY AND HIGHER EDUCATION  
ADDRESSING GRAND SOCIETAL  
CHALLENGES TOGETHER

## Logic model

- Facilitate situation & needs analysis
- Help refine the research question
- Support team to plan for impact
- Agree targets for intended effect
- Identify inputs & activities
- Allow allocation of resources
- Clearly identify outputs
- Outcomes are the anticipated short-term results of the research project
- Outcomes intermediate steps towards impact



Key stakeholders	Inputs	Activities	Outcomes	Impacts
Children Parents Family members and friends of children & parents Healthcare workers (including but not limited to nurses, doctors, physiotherapists, pharmacists, psychologists, dietitians) Social work service workers Organisations/ associations related to healthcare condition Academic staff Other influencers	Funding (to facilitate space, parking/transport, food, drinks, resources, training, form of reimbursement etc) Space (easy to access) Staff and possible facilitators Resources Training Support from Clinical Director of the PICU and Director of Nursing ? equipment (laptops with speakers etc, projectors) ? support workers to help care for children while parents participate in the group	Training and education for both PPI members and staff (? Need for re-fresher sessions) Develop and agree ToR's (review once a year) (this will depend on how the group wishes to interact, i.e. face-to-face or email) Review research and audit proposals and protocols every four months and provide their feedback	Parent PPI group shares their ideas/ opinions/ advice on research and audit proposals Parent PPI group shares their ideas/ opinions/ advice on research and audit protocols CYP PPI group shares their ideas/ opinions/ advice on research and audit proposals CYP PPI group shares their ideas/ opinions/ advice on research and audit protocols	To include the knowledge and experience of parents and patients of the PICU when developing research and audit proposals and protocols.

# Conclusion

- Through the development and embedding of PIPPIN we hope to work with people who are seldom heard, to bring value and meaning to our research and education activities. We will strive to capture and share best PPI research practice.



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