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Parent, Child and Public Involvement in Child Health Research: Core value not just an optional extra

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Title: Parent, Child and Public Involvement in Child Health Research: Core value not just an optional extra

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The rights of the child

Health care professionals are advocates for families and children but have no consistent framework research involvement. The Convention on the Rights of the Child (CRC) enshrined "The right to an opinion" stating that all children have the right to express their views. They also have the right to be informed and give their opinion about the world around them (1) Here we discuss Patient-Public Involvement (PPI) in research and why it is important and provide a framework to assist healthcare professionals.

What is PPI

Patients' and public involvement (PPI), (2) means involving anyone not professionally interested or experienced in health and care in research. Public involvement, PI, is another term often used which describes initiatives to give lay people an effective, active role in health and care research. PPI and PI have similar goals: to develop research that addresses patients' and the public's needs, and thereby improve the success, cost-effectiveness and impact of research. Furthermore, close involvement of patients and the public can facilitate rapid dissemination and implementation of research findings.

Patient and public (and parent) involvement in medical research differs considerably between countries, as well as between patient groups, medical specialties and institutions. The use of different terminology and definitions in different countries has contributed to this variation (3). Similar types of patient and family involvement are termed *engagement* in North America and *participation* in the Netherlands whereas the UK National Institute for Health Research (NIHR) divides different activities into *engagement*, *involvement*, and *participation* depending on their nature (4). Involving children research adds another layer of complexity as terminology needs to include infants, children, teenagers and young adults as well as their families.

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3 Organisations and initiatives such as iCan (International Children Advisory Network:
4 a global consortium of Youth Advisory Groups) and NIHR Generation R are dedicated to
5 providing a voice for children and families in pediatric medicine and research, and provide
6 resources, advice and examples effective PPI(5).
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9 ***Why is it essential ...what is the evidence***

10 Advocacy and patient participation are becoming increasingly integrated in child
11 health research and practice as health care moves to embrace family-centred models of
12 care. This, and the move towards meaningful PPI in research more generally, has highlighted
13 the high degree to which such children and their families would like to be involved in future
14 research. During the creation of the Royal College of Paediatrics and Child Health (RCPCH)
15 research charter, children and their families (6) clearly indicated that they wanted to
16 participate in the planning, design and implementation of research projects. Furthermore,
17 there is good evidence that research that integrates meaningful PPI – research performed
18 with or by the research participants rather than on them – leads to tangible benefits for
19 researchers ranging from better trial recruitment and retention (7) to enhanced research
20 impact.
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25 ***How to do this?***

26 Developing partnership between families, children, the public and health care
27 workers is essential across the research process, from research priority setting, clinical trial
28 design, ethics, medical publishing, medical conferences, through to policy.
29 There are paediatric and neonatal examples of high quality PPI that cover the different
30 stages of the research cycle. Following a framework developed by the James Lind Alliance
31 (8), parents, patients and the public have been involved in identifying priorities to be
32 addressed in future preterm birth research. In relation to trial design, the Core Outcome
33 Measures in Effectiveness Trials (COMET) Initiative has developed a comprehensive
34 handbook to guide researchers seeking to develop core outcome sets for use across clinical
35 trials, a key component of which is parent and patient involvement (9,10). Research funders
36 are increasingly supporting these initiatives, for example the primary funder of medical
37 research in the United Kingdom, the NIHR, mandates reference to both core outcome sets
38 and James Lind Alliance priority setting partnerships where they exist, when funding clinical
39 trials.
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44 Meaningful parent, patient and public involvement is increasingly required when
45 publishing research. Medical journals are increasingly modifying their editorial policies to
46 recognise the importance of PPI – the British Medical Journal's campaign for patient-
47 partnership is an excellent example of collaboration in this area(10). In *Pediatric Research*
48 we have started this journey by introducing parent perspectives to complement papers
49 published in the journal. Another suggestion is the inclusion of a lay summary in all
50 manuscripts to improve accessibility. Medical conferences are also changing to recognise
51 and value PPI such as the Cochrane colloquium (11) to ensure there is a patient in the
52 programme, on the stage and in the audience. The European Foundation for the Care of
53 Newborn Infants ahv developed a guide for parents on research which provides guidance on
54 meaningful engagement of families in research projects (12)

55 Financial and educational resources are needed to allow researchers, families and children
56 to engage in collaborative research. Funding mechanism exist from the NIHR and Wellcome
57 Trust in the UK as well as Patient-Centered Outcomes Research Institute (PCORI);
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3 <https://www.pcori.org/>) in the USA which provide support to researchers and families
4 engaging in PPI research. Resources such as guidance notes, and practical advice on costing
5 and publication libraries have been established by the NIHR the INVOLVE group(13).
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8 As paediatricians, neonatologists and researchers in child health we work closely with
9 parents, patients and families routinely and continuously to provide the optimal care for all
10 children, and are privileged to be allowed fulfil this role. High quality evidence suggests that
11 applying this approach to academic paediatrics and neonatology leads to better, more
12 applicable and impactful research. The benefits to children and their families from
13 participation in research projects may be augmented by involvement in all aspects of the
14 project from its inception to publication and implementation, and be a source of
15 empowerment.
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