American Academy of Cerebral Palsy and Developmental Medicine 69th Annual Conference
Instructional Course 8
Thursday, October 22 4:00-6:00 pm

**Family-Researcher Collaboration: Bringing the Family's Voice to Research**

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**Purpose:** To provide background knowledge on including key stakeholders as members of the research team and share the presenters’ (parents of children with cerebral palsy and clinical researchers) experiences conducting large, multisite studies of parents and children with cerebral palsy. A desired outcome is for course participants to envision innovative possibilities for family-researcher collaborations.

**Course Summary:** Parents and families are key stakeholders in research related to children and youth with disabilities. Although family-centered services are recognized as best practice, advocacy for engaging families in research is still emerging. Including parents on the research team may better address consumer priorities, ensure interventions are feasible and acceptable to children and families, and lead to dissemination of findings in ways that enhance use by families and practitioners. Family-researcher collaboration, however, is not without challenges. The presenters’ will: a) provide background knowledge on including parent stakeholders as members of the research team, b) summarize models for stakeholder participation (e.g. consultative, collaborative), c) share their research team’s experiences, and d) engage course participants in discussion of challenges to family-researcher collaboration and solutions to challenges.

**Learning Objectives**

- Describe the rationale for including parents or family stakeholders as members of the research team and models for stakeholder participation
- Discuss parent perspectives on participation in research
- Describe successes, challenges, and solutions to family-researcher collaboration
- Develop and Implement strategies for engagement of family members in research
Course Outline:

- Introduction and overview of objectives - Robert Palisano
- Including stakeholders as members of the research team; models for stakeholder participation - Lisa Chiarello
- Building relationships and interacting with parents - Tina Hjorngaard and Barbara Sieck Taylor
- Overview of “Move & Play” and “On Track” studies: Why engage parents? - Robert Palisano
- Experience of parent members of the research team - Tina Hjorngaard and Barbara Sieck Taylor
- What have the researchers learned? - Lisa Chiarello and Robert Palisano
- Interactive discussion with course participants: Successes, challenges, solutions to challenges, and envisioning the possibilities
- Take home messages

QUESTIONS FOR REFLECTION AND DISCUSSION

We will address the following questions for our research collaboration and encourage course participants to share their perspectives and experiences during the discussion.

- What is your perspective on the value of engaging families as part of the research team or in program development/evaluation of a clinical service?

- How would you engage family members as part of a research team or in program development/evaluation of a clinical service?

- What aspects of the research or program development/evaluation process would you engage family members?

- How can researchers/professionals interact to support a valued relationship among family and other members of the team?

- How can researchers/professionals support sustained involvement and collaboration with family members of the team?
BACKGROUND INFORMATION AND RESOURCES

Why Engage Families in Research?

Rosenbaum (2011)
- Family-centered Research – partnerships that “build on family and researcher expertise more equally from the start”


Morris, Shilling, McHugh, Wyatt (2011)
- “Families should be involved in deciding the research agenda as the research concerns them and those in similar life circumstances”
- “Families more likely to want to take part in research that address their own priorities and do so using research procedures that are designed to be acceptable to them.”
- Mandatory in UK when applying for government sponsored research

Morris C, Shilling V, McHugh C, Wyatt K. Why it is crucial to involve families in all stages of childhood disability research. Letter to the editor. Dev Med Child Neurol. 2011; 1-3

Organizations Supporting Patient and Stakeholder Engagement in Research

INVOLVE (UNITED KINGDOM)
http://www.invo.org.uk/

INVOLVE is a national advisory group funded by the National Institute for Health Research, UK since 1996 to support active public involvement in national health system, public health, and social care research. Aim: to advance public involvement in research considered to be an “essential part of the process by which research is identified, prioritized, designed, conducted and disseminated.”

“INVOLVE defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritize research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.” (retrieved September 2, 2015 from http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/).

The web-site contains useful information and resources.

INVOLVE Strategy 2012 – 2015: Putting People First in Research
Briefing Notes for Researchers
http://www.invo.org.uk/resource-centre/resource-for-researchers/

Guidelines on Use of Social Media to Actively Involve People in Research
http://www.invo.org.uk/posttypepublication/guidance-on-the-use-of-social-media/

JAMES LIND ALLIANCE (UNITED KINGDOM)
http://www.jla.nihr.ac.uk/

A non-profit making initiative established in 2004 to brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important.

The James Lind Alliance facilitates Priority Setting Partnerships among patients, carers, and clinician groups to:

- Identify treatment uncertainties which are important to all groups
- Work with all groups to prioritize the uncertainties
- Produce a final list of jointly agreed research priorities and publicize them widely

James Lind Alliance Guidebook
http://www.jla.nihr.ac.uk/guidebook

Priorities for Childhood Disability
http://www.jla.nihr.ac.uk/top-tens/cleft-lip-and-palate-top-11

Templates and Useful Documents

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (USA)
http://www.pcori.org/

The Patient-Centered Outcomes Research Institute (PCORI) was established by the US Congress through the 2010 Patient Protection and Affordable Care Act as an independent, non-profit organization. PCORI’s mission is to help people make informed health care decisions by producing and promoting high integrity, evidence-based information – that comes from research guided by patients, caregivers and the broader health care community. PCORI’s aim is research that is responsive to the preferences, values and experiences of patients in making health care decisions and the impact diseases and conditions can have on daily life. Consequently funded research should include patients and other stakeholders in each step of the research process—from proposal development to research design and dissemination of the study results.

PCORI Methodology Report
Patients/stakeholder Roles:

- Patient/Stakeholder Co-Investigator
- Patient/Stakeholder research team member (consultants, advisors, technical experts)
- Advisory group
- Group Forum
- Complete survey or questionnaire to provide input on the research process

Patients/stakeholder Contributions:

- **Information:** Researcher(s) describe decisions to patients and other stakeholder partners after decisions are made.
- **Consultation:** Patients and other stakeholders provide feedback to researchers that can inform decision-making. Consultation allows the researcher to obtain views without necessarily being committed to act on them.
- **Collaboration:** Researchers, patients and other stakeholders have an active partnership. Patients and other stakeholders work directly with the researcher to ensure that their perspectives are consistently understood and incorporated in decision making, and have greater ownership of the project.
- **Patient/stakeholder direction:** also known as “user control,” patients and other stakeholder(s) are empowered to have control over the research process and the final decision-making.

THE PENINSULA CEREBRA RESEARCH UNIT (ENGLAND)


The Peninsula Cerebra Research Unit for Childhood Disability Research in the South West of England seeks to carry out research that families with disabled children think is useful and relevant to their lives. Families of children with disabilities are involved in all research and related activities.

Children’s Perspectives – Anna’s and Jack’s Story (told in their voices using a picture book)[http://www.pencru.org/research/fromachildsperspective/](http://www.pencru.org/research/fromachildsperspective/)
RESEARCH SUMMARIES


Twenty-two papers were included in the review and 9 examples of how children were involved in research were identified. Recommendations included: a) effective communication, b) flexibility and adaptation of methods to address the preferences and needs of children, and c) sufficient funds to support involvement. Involvement of children with non-verbal communication was identified as a particular challenge. Few studies evaluated how children and youth were engaged in research. The potential positive impact primarily represented authors’ opinions.


A scoping review identified 19 articles describing stakeholder engagement in research. Stakeholder engagement was influenced by several factors including communication, power sharing, and resources. Desired outcomes of stakeholder engagement included: empowering stakeholders, stakeholder-researcher partnerships, facilitating the research process, and application of findings. There was limited data on actual outcomes.


This article presents the inaugural comparative effectiveness research cohort study of Washington State’s Comparative Effectiveness Research Translation Network that includes a patient advisory board. A conceptual framework for patient-centered outcomes research is described.


There is limited research on the value and impact of patient and stakeholder engagement in research. The authors’ review literature on hypothesized impacts of engagement, what has been evaluated, and identify steps needed to determine the effects of patient and stakeholder engagement.

An online survey of patients (n = 900) and primary care clinicians (n = 750) was conducted. Patients (66%) and clinicians (55%) indicated interest in engagement as research partners. Lack of time was most often cited as a barrier.


Patients and other stakeholders were most commonly engaged to identify patient-centered research agendas, to select which study outcomes were important to patients, to provide input on study design, and to identify strategies for increasing enrollment in trials. No quantitative data on the effectiveness of engagement practices were found.


Research published through 2010 was reviewed and interviews were conducted with 15 key informants from research and policy making organizations in the United States, Canada, and the United Kingdom. An extensive checklist for reporting stakeholder engage was developed.