

The Research Home: Partnering with Families



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The author declares that he has no conflict of interest.

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I WANT TO express my gratitude to the members of the Research Committee for considering me suitable to receive this prestigious award.

All of us are familiar with the concept of the medical home for providing personalized health care for children. The Academic Pediatric Association has been one of its principal sponsors and supporters.

In the medical home, care is accessible, continuous, comprehensive, and coordinated with subspecialists, nurses, and other nonphysician providers who play important roles, as well as with community agencies and schools. Care is compassionate and culturally sensitive, responsive to special needs arising from families' backgrounds, language, and culture. As part of the medical home, we educate parents about their child's condition. We strive to provide care that is personalized, ensuring that the child and the parent feel important and special. We involve parents, and to the extent possible their children, in decision making. We believe that this concept of care provides substantial benefit to the child and family (Table).

I would now like to spend the next few minutes discussing an analogous concept that my colleague Evelyn Reis has termed the research home. In the traditional approach to clinical research, individuals enrolled in studies are considered passive subjects in a protocol. To elevate children and their families to the level of partners, we change our frame of reference. We note that many similarities exist between the medical home and the research home. A difference, however, is that the beneficiaries of the research home include not only the individual child and family but also children, families, and society generally, as well as health care workers at various levels who receive additional training in order to carry out their research roles.

I believe that building a community of research-engaged participants and their families can lead to increased research participation, as well as improved knowledge and more ready adoption of research-based practices, and can enhance trust in research and scientific behaviors. Let me share with you some of our efforts aimed at developing this research home.

First, I will describe a practice-based research network we established in community pediatric offices. Pediatric

PittNet involves 200 pediatric providers and approximately 200,000 covered children and adolescents. The network receives infrastructure support from the Clinical Translational Science Institute of the University of Pittsburgh. PittNet's executive group includes researchers in the physical health and mental health clinical programs, research managers, administrators, and community practitioners. These practitioners have a strong voice in the program's operation; they lead research initiatives within their own practices, decide in which practices what studies are appropriate, and where research coordinators are placed. We, as academic pediatricians, also serve as role models and early adopters for innovations that enhance quality of care. This program exemplifies both accessibility and coordination of research efforts, involving physicians whom families know and with whom a partnership of mutual responsibility and trust exists.

Let me tell you next about our effort to bring research as close as we can to the family's actual home (Fig. 1). When specific imaging or procedures are required as part of a study, research visits are necessarily conducted at the hospital. However, in many instances research visits do not require high-powered technology. Accordingly, we developed a Mobile Research Service for parents who prefer to have research visits at one of the children's hospital satellites, at a pediatric office closer to their home, or even at the family's home. The service consists of research coordinators from various divisions within the department of pediatrics, who are cross-trained for various protocols and conduct the research visit at the family's home. Always our goal is to keep the child and family at the center of our thinking—as in the case of the medical home, our efforts are directed to the extent possible to accommodate the needs of the child and the family, again providing examples of coordinated and accessible care.

Our trained research staff members carry out educational functions as well. For example, our coordinators train nurse practitioners, physician assistants, and nurses at pediatric offices in proper technique for performing bladder catheterization. They are instrumental in teaching residents (and faculty at times) proper technique for cerumen removal. And they instruct practice personnel in obtaining pulmonary function tests. The beneficiaries of

Table. Concept of Care

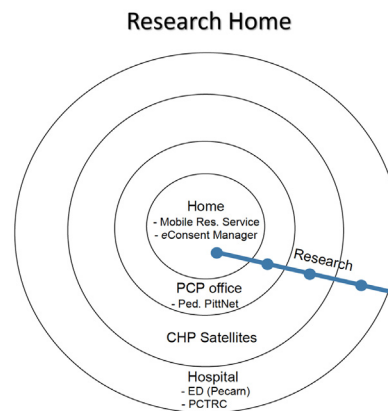
Medical Home	Research Home
Care	Care
Accessible	Accessible
Continuous	Continuous
Comprehensive	Comprehensive
Coordinated	Coordinated
Compassionate and culturally sensitive	Compassionate and culturally sensitive
Educational	Educational
Physician	Physician
Known personally to the family	Known personally to the family
Partnership with mutual responsibility and trust	Partnership with mutual responsibility and trust
Beneficiaries	Beneficiaries
Individual child and family	Individual child and family
	Children, families, and society generally
	Health care workers (education)

this program are thus extended to include office health care workers, whose educations are enhanced.

Let me mention next our creation of treatment centers anchored around research expertise in a couple of areas—namely, urinary tract infection (UTI) and otitis media. The UTI center (Fig. 2, www.chp.edu/utis) incorporates quality improvement initiatives regarding diagnosis, imaging, and management for children with UTIs and with bladder and bowel dysfunction, and it provides ready consultation with specialists in nephrology, urology, and infectious diseases. Laboratory and imaging results are immediately communicated back to the family and the primary care provider.

In otitis media, we have placed otoendoscopes at specific practices where research is conducted and where they are used to capture digital images of the tympanic membrane (Fig. 3). These can be reviewed remotely, to enhance diagnostic accuracy and to support appropriate management. Primary care providers often refer children failing antimicrobial therapy for diagnostic tympanocentesis. Here again, enhanced, evidence-based, high-quality care results from coordination of services.

I would like to touch briefly on the informed consent process. We have tried to learn from parents what factors influence their decision to participate in clinical research.¹ In the Randomized Intervention for Vesicoureteral Reflux study, published in the *New England Journal of Medicine*,² 120 parents, of whom half consented and half declined participation, completed an anonymous survey. Parents who declined consent had higher socioeconomic status, were more likely to have private health insurance, and exhibited more anxiety about their decision compared with consenting parents. Consenting parents were more likely than nonconsenting parents to perceive the researcher as professional. They had higher levels of trust and of altruism; they were more likely to perceive the potential for their child receiving enhanced care; they reflected better understanding of randomization, blinding, and the right to withdraw; and they exhibited lower decisional uncertainty. Awareness of these factors should help researchers



PCP: primary care provider; CHP: Children's Hospital of Pittsburgh; ED: emergency department; PCTRC: pediatric clinical and translational research center

Figure 1. Research Home.

tailor their discussions about consent with parents, and also should enhance the overall quality of the informed consent process and result in improved participation in pediatric clinical trials.

In the same vein, and in the interest of further empowering families, we are developing a software program called eConsent Manager. This program includes, among other elements, an institutional review board–approved consent document presented dynamically. It will permit video conferencing with the researcher and will show animated videos about specific study procedures. It will also provide alerts when a revised consent document is needed, and at completion, will trigger our data management system to initiate collection of research data. Again, compassionate and culturally sensitive care with comprehensive parental education will result.

The research home needs to feel homelike. At initial registration in the clinic, we enroll families in a Clinical and Translational Science Institute–sponsored research participant registry. Families receive a welcome package with a checklist of potential research areas of interest. Participation ensures that they will receive information about studies that might interest them and that match their child's diagnoses. Quarterly newsletters highlight specific studies and communicate research findings. We help parents set up in their cell phones a patient portal app to enable notification of upcoming visits, test results, immunization records, preventive care reminders, medication refills, and e-mail access to the office. We will also share information about research studies being conducted. Large screens in the waiting areas display a consistent video feed highlighting the importance of immunizations and discussing how participating in research contributes to evidence-based medical care. The research home should provide an ongoing positive and inclusive research message across the care continuum. Starting at the prenatal visit, we want parents to expect that they will be presented with opportunities to participate in research.

UTI Center

Children's Hospital of Pittsburgh of UPMC

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UTI Center

A Center for Care and Investigation of Pediatric Urinary Tract Infections

The UTI Center at Children's Hospital of Pittsburgh of UPMC takes a multidisciplinary approach to addressing and investigating pediatric urinary tract infections (UTI). This creates a unique setting for providing the highest level of clinical care and research.

A resource for families and clinical partners in the community, the Center focuses on UTI and the related conditions of vesicoureteral reflux and bladder and bowel dysfunction. With more than two decades of experience caring for children with UTI, our nationally recognized researchers have changed common practices for treating UTI, improving the lives of children in the process.

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Last Update
August 19, 2013

Figure 2. Urinary Tract Infection Center (UTI Center; www.chp.edu/utis).

We have reframed the idea of being a passive subject in a research study, as illustrated by previous consent documents that “invite you to participate in, or support, *our* study.” In contrast, in our interactions with parents, we address what we know about the condition their child has, what we have learned from recent research, what we do not know and accordingly where equipoise exists, and how we intend to address this lack of knowledge through a high-quality and safe research program. We invite the family to become our partner, not our subject.

In the research home, children and families are at the center of the cycle of clinical research (Fig. 4). Families learn how current practices arose from previous research, learn about findings from recent studies, and learn about opportunities for future participation; they influence ideas and clinical problems to be studied; they help us understand how to enhance recruitment and retention; and they participate in ongoing research as informed, engaged members of the team in a partnership of mutual responsibility and trust with the investigator. Finally, in entering the research home, we believe that they also benefit from

Left Ear	EAR EXAM	Right Ear
<input checked="" type="radio"/> Intact <input type="radio"/> Perforated <input type="radio"/> Tubes	TM	<input checked="" type="radio"/> Intact <input type="radio"/> Perforated <input type="radio"/> Tubes
<input type="checkbox"/> Gray <input checked="" type="checkbox"/> White <input type="checkbox"/> Pink <input type="checkbox"/> Amber <input type="checkbox"/> Pale yellow <input type="checkbox"/> Blue	Color (Check all that apply)	<input type="checkbox"/> Gray <input checked="" type="checkbox"/> White <input type="checkbox"/> Pink <input type="checkbox"/> Amber <input type="checkbox"/> Pale yellow <input type="checkbox"/> Blue
<input type="radio"/> Translucent <input type="radio"/> Semi-opaque <input checked="" type="radio"/> Opaque	Translucency	<input type="radio"/> Translucent <input type="radio"/> Semi-opaque <input checked="" type="radio"/> Opaque
<input checked="" type="radio"/> None <input type="radio"/> 1+ <input type="radio"/> 3+ <input type="radio"/> 2+ <input type="radio"/> 4+	Mobility	<input checked="" type="radio"/> None <input type="radio"/> 1+ <input type="radio"/> 3+ <input type="radio"/> 2+ <input type="radio"/> 4+
<input type="radio"/> Yes <input checked="" type="radio"/> No	Air Fluid Interface	<input type="radio"/> Yes <input checked="" type="radio"/> No
<input checked="" type="radio"/> Yes <input type="radio"/> No	Otalgia	<input checked="" type="radio"/> Yes <input type="radio"/> No
<input type="radio"/> Yes <input checked="" type="radio"/> No	Distinct erythema	<input type="radio"/> Yes <input checked="" type="radio"/> No
<input type="radio"/> Neutral <input type="radio"/> 1+ Bulging <input type="radio"/> Retracted <input type="radio"/> 2+ Bulging <input checked="" type="radio"/> 3+ Bulging	Position	<input type="radio"/> Neutral <input type="radio"/> 1+ Bulging <input type="radio"/> Retracted <input type="radio"/> 2+ Bulging <input checked="" type="radio"/> 3+ Bulging
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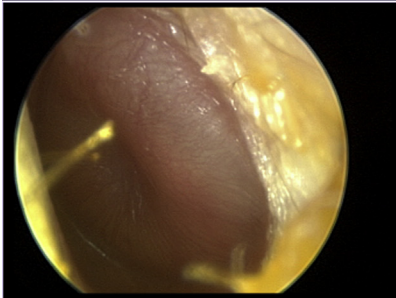
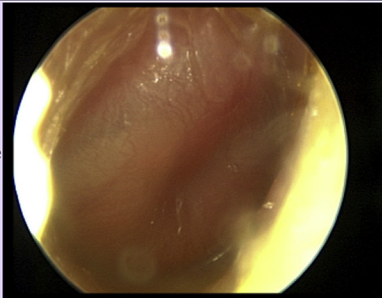

Image


Figure 3. Ear exam form including digital images of the tympanic membrane.

the enhanced clinical care that is an integral part of many study protocols.

These concepts emerge from what I learned in research kindergarten when David Keller and I were fellows in ambulatory pediatrics and community medicine under Jack Paradise, who received this research award exactly 20 years ago. I remember watching Jack allocating suffi-

cient time to conduct a careful examination, sitting close to parents at eye level to discuss clinical findings, what we knew, what we did not know, and what we were trying to learn in order to provide better, evidence-based care for their children and future generations of children. His personal touch and connection with families enabled trust and understanding that the research team would hold the participant’s best interest paramount, would provide comprehensive medical care, and would be available 24/7 for any concerns they might have. These encounters always ended with a phrase I have stolen from Jack and continue to use: “At the end of the day, you [the parent] need to do whatever you feel most comfortable with for your child.”

I am indebted to all of our research participants and their families; to my mentors in research, Jack Paradise, Ken Rogers, and Ellen Wald; to my chair, David Perlmutter; to faculty members of the Division of General Academic Pediatrics; to our community practitioner partners; and to my entire research team, all of whom enable on a daily basis this unique research program that I am most proud of. I have no words to express my love and gratitude to my wife, Barbara, and my sons, Julian, Martin, and Andy, who have experienced over the past 25 years my absences and short attention span as I struggle with grants and manuscript

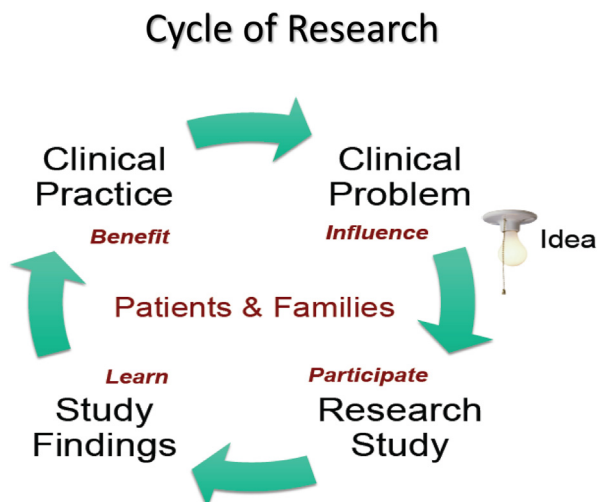


Figure 4. Cycle of clinical research.

submissions, as well as parents' calls at all hours on my cell phone. Thank you once more; I am truly honored to be here today.

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