

## Research with Patients and Families

*A research project can be constructed as an elective for a medical student or a resident with a patient- and family-advisory group as the major resource. A student or resident interested in patient/physician relationships and communication or patient and family perspectives on medical care can formulate a research question that involves partnering with parents of children with special needs or adults with chronic conditions. Research projects can address widely diverse topics such as the following:*

- *The role of music in enhancing language development in children with autism.*
- *How to write an understandable and respectful consent form for parents for a study of serous otitis.*
- *How to write a guide for parents of children newly diagnosed with autism.*
- *Patients' advice for medical students and physicians about doing a helpful medical interview.*
- *How to present news of a cardiac murmur to parents.*

*Medical students may carry their initial research interest into their residencies and residents into their fellowships and careers.*

## Goals

1. To provide a supportive environment for medical students or residents to explore their ideas with parent and adult patient colleagues.
2. To involve medical students or residents with parents or patients as individuals in home visits, interviews, and/or focus groups.
3. To provide an opportunity for medical students or residents to practice formulating a research question, interviewing, facilitating focus groups, and/or analyzing data.
4. To provide an opportunity for medical students or residents to experience self-directed learning in the context of doing research.
5. To provide students or residents with opportunities to present research in a professional forum.



## Objectives

Medical students or residents will:

1. Choose, design, and implement a research project that involves patients and/or families as collaborators and/or informants.
2. Produce a written research product.

## Description of the Activity

When a student or resident expresses an interest in research, a faculty member meets with the learner to plan the project. The faculty member ensures that the project incorporates the expertise of a group of patient- or family-advisors, is feasible in the proposed time-frame, and will result in a concrete product (a paper, poster, research proposal, or presentation). The project should focus on ways to access the expertise of the parent- and patient-advisors with their unique knowledge and insights about healthcare situations. The concept that patients and family members can help formulate research questions and plans as well as offer insights about health care that cannot be obtained from other sources is often a new and unexpected perspective for students or residents. Encountering this perspective in the context of research encourages an attitude that patients and their families are valuable allies in the delivery of health care with useful information to share.

The time spent in a research elective may vary according to the structure of a medical school's curriculum. The shortest practical amount of time for a meaningful project is about a month, and that requires some pre-planning of the project, particularly if approval

### *Description of Research Elective in Medical School Catalog:*

In consultation with faculty, students will develop an individualized approach to acquire knowledge and skills for research. Students may participate in ongoing basic or educational research with Department of Pediatrics faculty or design and carry out a small research project using an existing database of children with special healthcare needs and their families or adults with extensive healthcare experience.

*Uniformed Services University of the Health Sciences catalog*

is required from an institutional review board (IRB) that oversees protection of human participants in research. Some medical school curricula may allow for longer electives. Some medical students may be able to decide on a project, draft a plan, and request IRB approval in advance to enable them to focus on interviews or focus groups and then on writ-

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ing a paper during a month-long elective. Other students may spend a month-long elective refining a research question and methodology, then implement their protocol during their residency. Residents may extend their involvement in a research project over the three years of residency.

Sometimes students or residents are uncertain about the topic they would like to pursue. Faculty then work with the learner to determine if any of the following suggests a research topic of interest:

1. A medical topic of growing interest to the learner.
2. A skill the learner has identified that he or she wants to improve.
3. A personal attitude or set of skills the learner would like to improve regarding patient/physician or parent/physician relationship and communication.
4. A research technique the student would like to apply and understand.

Prior approval by the IRB of a protocol that involves a patient- and parent-advisory group facilitates approval of short research projects. With an on-going protocol as a framework, short-term research projects may be approved as modifications of the larger protocol. If participation in the types of activities covered in a research elective for medical students is explicitly mentioned in the consent form for advisory groups, additional consent forms may not be required.



In summary, the steps of this research activity include the following:

1. Meet with the student or resident to ascertain research interests and discuss how to formulate a clear research question.
2. Discuss how patients or family members could inform the research process or topic of interest to the learner.
3. Discuss potential products that the learner could develop from this research project (a paper, article, poster presentation, platform presentation proposal, full research protocol, items for a survey instrument, consent form reviewed by patients or families, literature review, etc.).
4. Ask the learner to develop a specific plan to pursue this research. Minimal requirements for the plan include the following:
  - Research topic.
  - Formulation of a research question.

- An activity that involves patients or families in some way.
  - Plan for a concrete product.
5. Assess the feasibility of the plan in the timeframe available to the learner.
  6. Pursue necessary IRB approval.
  7. Facilitate access to patients or families who can inform the topic of the learner's research.
  8. Provide feedback to the learner as the project proceeds.

### **The Role of Patient- and Family-Advisors**

Parent- and patient-advisors may participate in research in several ways. The student's or resident's research objective may be a theme or question generated or refined by an advisory group. The advisory group may also participate in focus groups, home visits, surveys, and editing of research reports or papers. Students and residents learn that parents and adult patients have important information about health care and valuable insights about relationships with physicians. They also gain insights important to self-awareness, communication with patients and families, shared medical decision-making, and advocacy as they apply to research topics of interest to them.

*"Parents' sense of responsibility in contributing towards the decision-making of their child's medical care must be recognized by the pediatrician and influence non-judgmental discussions of the use of alternative medical approaches."*

—a medical student

## **Informing Medical Students and Residents about Research Opportunities**

Medical students may be invited to participate in a research opportunity during a clerkship or course. Residency program directors may present opportunities for collaborative research with patient- and family-advisors when describing the research requirement of a residency. Sample descriptions of a research opportunity appear below.

### *Sample Flyer Describing Research Opportunities*

#### *The Family Competency Project: Research and Practicum Opportunities for Fourth-Year Students*

The Department of Pediatrics offers individualized, learner-centered opportunities to learn about families and children in community and home settings and to explore and develop research topics relevant to children and families. Dr. Janice Hanson and Dr. Virginia Randall co-direct this project. Opportunities include the following:

- Meet for lunch to discuss how to develop a good research question.
- Develop an outline for a research proposal.
- Learn about qualitative research methodology.
- Discuss various research designs and how to choose one that matches your research question.
- Follow a family over 2–3 years, meeting for conversations over dinner to build an understanding of the questions, concerns, celebrations, challenges, and triumphs they experience, and how these relate to good medical care.
- Visit children and families in community programs (special education, day care, community-based occupational, physical or speech therapy, school, sports, play groups, etc.).
- Develop and implement an interview-based research project.
- Receive one-to-one comments and suggestions for writing and publishing a paper.
- Meet with a focus group of parents to explore a topic of interest.
- Develop a parent education handout with parent input.
- Practice physician-parent or physician-patient communication with parent or patient feedback.
- Help to analyze and interpret existing survey or interview data.

We have available a group of about 100 families who have children with disabilities or chronic health conditions who are willing to serve as advisors and teachers in situations like these. Many of these families also have other children who do not have special healthcare needs. We will meet with you to tailor a learning experience that matches your interests and needs. For more information, drop by Room C-1081 or call Dr. Hanson (xxx) \_\_\_\_\_ or Dr. Randall (xxx) \_\_\_\_\_.

## Examples of Research Projects that Involve Patient- or Family-Advisors

The range of research topics that students and residents can pursue with patient- and family-advisors is extremely broad. The following summaries describe projects that have actually been completed, most of them by medical students. They illustrate the wide variety of ideas that can emerge and lead to research that addresses important questions.

### NOT SO COMMON SENSE:

*"I have spent the last couple weeks interviewing and speaking with many patients and families to learn something about patient perspectives on physicians. Although many of these lessons and thoughts seem obvious, almost easy, I know they are not. My actions need to have intentional focus on the patient because it is easy to get lost in the diagnosis, the treatment, or my own problems and issues. Being aware of this now will hopefully make me a better physician in the future..."*

—a medical student

### Projects Focused on Interviewing

**Research Question:** How do patients want their doctors to communicate during a medical interview? **Method:** In-home and telephone interviews with parent- and patient-advisors using open-ended questions. **Product:** A paper summarizing patient perspectives and preferences for the medical interview.

**Research Question:** What can a medical student learn from patient narratives about their healthcare experiences? **Method:** In-home interviews with parent- and patient advisors to elicit stories from their healthcare experiences. **Product:** A paper recounting patient stories, each followed by the medical student's statement about the ways she hopes to interact with patients during her career as a physician as a result of hearing these stories.

**Research Question:** How might music and/or music therapy facilitate language and social development for children with autism? **Method:** Home visits to four families with children with autism to observe the children with their parents, interview parents, and observe the children's responses to singing and guitar music. **Products:** A tentative theory about the development of music appreciation, language, and social interactions in children with autism; a presentation at a regional meeting of the Ambulatory Pediatrics Association; draft of a research proposal for residency.

**Research Question:** How might a pediatrician's personal attitudes about body piercing affect clinical interactions with adolescents? **Method:** Informal observations at a body piercing and tattoo parlor, in-home interviews with adolescents. **Product:** A thoughtful paper with personal reflections about attitudes and responses to adolescents.

### Projects Focused on Research Methodologies

**Research Question:** How do parents make decisions about whether to use complementary and alternative medicine? **Method:** Analyze existing survey data. **Product:** A concept map that describes parents' decision-making process and two presentations during residents' conferences.

**Research Question:** How can an informed consent form for a study about using nasal insufflators to prevent otitis media with effusion be worded in such a way that parents understand it and can make an informed decision about their child's participation? What features of the study would make it feasible and acceptable for parents? **Method:** A focus group of parents who reviewed a draft research protocol and consent form. **Product:** A revised research protocol and consent form.

**Research Question:** What services do medically fragile children and families need and receive in the military health system? **Method:** Interviews with 6 parents of medically fragile children or children who have died. **Product:** A paper summarizing themes of these interviews.



### Projects Using Focus Groups as the Primary Data Source

**Research Question:** What do parents of children with congenital heart disease recommend about how to tell a parent that his or her child has a heart murmur? **Method:** A focus group of parents with children with congenital heart disease. **Product:** A summary of recommendations for communicating with parents of children who have heart murmurs.

**Research Question:** What information do parents want when their child is diagnosed with autism? **Method:** Attend a conference on autism with parents of children with autism and hold a focus group with these parents after the conference. **Product:** An informational booklet for parents of newly-diagnosed children with advice and information recommended by veteran parents of children with autism.

**Research Question:** What information and suggestions can pediatricians share with adolescent parents to help prevent frustrated parents from physically harming their children? **Method:** Focus groups with parents to discuss how they constructively handle anger and frustration with their children. **Product:** A paper summarizing information for parents

about handling frustrations with their children and suggestions for conveying this information to adolescent parents.

**Research Question:** What kind of a pain rating scale would help parents of nonverbal children communicate effectively on behalf of their children? **Method:** Development of a research protocol that would use focus groups of parents. **Product:** A research protocol that could be implemented during residency.

*“How can the healthcare system best connect these families with the services they need [home nursing care, coordination of services, assistance with financial responsibilities, effect on siblings]? More often than not, they are left to fend for themselves.”*

—a medical student