5-15-2014

How to approach research: a guide for child life specialists

Emily L. Springer
Bank Street College of Education

Follow this and additional works at: http://educate.bankstreet.edu/independent-studies

Part of the Medicine and Health Sciences Commons

Recommended Citation
Retrieved from http://educate.bankstreet.edu/independent-studies/66
How to Approach Research:
A Guide for Child Life Specialists

By Emily L. Springer

Advisors:

Genevieve Lowry, M.Ed., CCLS
Bank Street College of Education
New York, NY

William J. Gostic, M.D.
Medical Intern at Kaiser Foundation Hospital
San Francisco, CA

Submitted in partial fulfillment of the requirements of the degree of Master of Science
Bank Street College of Education
2014
Abstract

It has been frequently noted that research is important to evaluate and validate child life interventions. Increasing the use of research studies may lead to strengthening the child life profession by analyzing interventions, demonstrating meaningful clinical outcomes, and disseminating that information amongst medical teams. Ultimately, this information could be used to improve the interventions that child life specialists provide to patients and families in the health care setting. The Child Life Council is a nonprofit professional association for child life specialists that organizes professional development opportunities and facilitates the exchange of knowledge and resources to aid in the growth of the field. The Child Life Council has recognized the importance of research and includes it in its main mission statement. However, a survey for child life specialists conducted by Dr. Joan Turner showed that many child life specialists lack the knowledge, experience, interest and/or confidence to participate in research activity. To aid in the solution of this problem, the Child Life Council and many child life specialists have developed tools to spread information about research such as the Anthology of Focus, Child Life Bulletin, research resources on the child life website, as well as compiling research studies that have been done by child life specialists in a monthly newsletter. As some of this information has not been consolidated into one resource yet or explained at a novice level, How to Approach Research: A Guide for Child Life Specialists, has been developed. This how-to guide aims to increase the understanding of research and provide child life specialists and students a concise and easy tool to access information about how they incorporate research into their work. This how-to guide is unique because it aims to encompass a variety of research terms, tools, and explanations. By raising the awareness of research, this guide may increase the quantity and
quality of research done by child life specialists, which will improve the interventions used with children involved with medical encounters as well as strengthen the growth of the field.
## Table of Contents

Abstract.................................................................................................................. p. 2-3  
Introduction........................................................................................................... 5-7  
Literature Review................................................................................................. 7-10  
Rationale............................................................................................................... 10-12  
How-To Guide.....................................................................................................  
Conclusion........................................................................................................... 12-14  
References.......................................................................................................... 15-16
Introduction

Child life specialists support the psychosocial needs of children in health care settings through interventions including preparation, procedural support, medical education, therapeutic play and expressive activities. These interventions improve the quality of care and support communication and the interpersonal dynamic between the patient and the health care team. Through these interventions child life specialists help hospitals meet the standards set by the Joint Commission on Accreditation of Healthcare Organizations to serve as a valuable asset (Joint Commission, 2004). Many child life specialists currently rely on their own expertise in child development to observe and assess a child’s behavior to evaluate the outcome of their interventions. However, it is understood that just as the medical team uses research studies to evaluate medical interventions, child life specialists should use research studies rather than anecdotal evidence to better assess and improve interventions as well as convey the benefits of child life to the interdisciplinary team.

Research is vital to improve the professional growth of individual child life specialists as well as strengthen the child life profession. Incorporating research as a rational and reliable tool, child life specialists can better evaluate the effects of their interventions to provide higher quality care for pediatric patients. Research can also be used as a way for child life specialists to share information with the medical team who are often trained to judge new treatments and interventions based on clinical trial and primary literature. Participating in research may create new job opportunities for child life specialists to demonstrate their role as integral team members. Research could also be used as a reliable way to share information between child life specialists.
The Child Life Council (CLC), the professional association for child life professionals, is beginning to recognize the importance of research. Among its many resources, the CLC has established the *Standards of Clinical Practice* (2001). These standards set a guideline for child life specialists, which outlines the full scope of services that child life specialists are responsible for maintaining (Crowell, 2009; Child Life Council). One standard included is *Research* (Section X). The CLC clearly states the importance of including research in clinical practice to validate methodologies and further the child life practice (childlife.org). Participating in research also supports the child life competency of representing and communicating child life practices and psychosocial issues to others (Child Life Council, 2002). The American Academy of Pediatrics agrees that child life specialists need to incorporate research to further demonstrate their ability to provide cost-effectiveness through helping reduce the length of stay and decreasing the need for sedation in pediatric patients (Wolfer, et. al.; Wilson & Goldberger).

The child life competencies framework is created for child life specialists to meet the standards of practice, however many child life specialists “see the role of clinician and researcher as mutually exclusive” (Crowell, 2009). Despite CLC’s strong push for participation in research activity, many child life specialists are not yet involved. A study in 2009 found that participation in research related activity was minimal, with only 13% involved in journal clubs, and 27% having professional experience with research (Turner, 2009). As many child life specialists come from diverse education backgrounds, it is no surprise that less than half, 45%, have participated in research during their undergraduate career. These results not only show that many child life specialists have not incorporated research into their professional careers, but also have not received the academic support and training to become competent in research. It is unreasonable to expect child life specialists to participate in research without the necessary training or
requiring research as a course in academic programs. Dr. Joan Turner, a child life specialist and researcher, believes that many child life specialists are not involved in research because of their intentions upon entering the field. Many join the field as a helping profession and do not have a drive for scholarly or academic work, due to their clinical focus. They also may feel that the research responsibilities will fall on someone else such as a director or manager of the child life department (Ianni, 2014).

Although there has been minimal research activity within the field, child life specialists understand that research could lead to positive outcomes (Turner, 2009). Child life specialists have strongly agreed that participating in research can lead to benefits such as enhancing child life career opportunities, instilling a sense of satisfaction, continuing professional development, providing meaningful contributions to the child life field, as well as increasing analytical skills (Turner, 2009). It seems that many child life professionals are facing a dilemma-they understand the importance of research, but lack the knowledge, support, resources, or confidence to initiate research projects. Many child life specialists have expressed confusion as to how to even begin to develop a research project (Crowell, 2009).

**Literature Review**

For many years, child life specialists have tried to become more involved in research. Starting in the 1930’s, play directors and play specialists across the country observed and systematically collected data regarding play, the use of toys, and the benefits of parental visitation for pediatric patients (Ianni 2014; Gaynard, *et. al.*, 1998; Prugh, *et. al.*, 1953; Gips, 1950; Langdon, 1948). The participation in research has been evolving since the beginning with
the pioneers of the child life field. Subsequently, various tools and resources have been generated for child life specialists to access.

The Child Life Council encourages the progression and dissemination of ideas amongst professionals in the field. Research resources are now available on the child life website which include a research needs report, an annotated bibliography, a list of online research resources, and information from the evidence-based practice committee. The CLC has also developed a CLC Research and Scholarship Committee. Every month, Child Life News Monthly releases pertinent research articles for members to view and use in their practice. The CLC has also published the Anthology of Focus, which includes numerous articles regarding research activity for child life specialists to learn from. Through this publication many child life specialists are able to share their research activity as well as provide guidance to others of how to navigate the realm of research.

Contributions have been made in effort to spark interest and provide information regarding research. Bivins and O’Brian discussed the importance and challenges of providing evidence-based practice, which can be used as a different method to approach research (2006). Several publications have been published to explain specific research terminology to novices, such as: variables (Koller, Mador, Lee, Gibson, 2008), Institutional Review Board (Hickey, 2010), and qualitative vs. quantitative studies (Crowell, 2009). Within the last year an article titled, “Frequently Asked Research Questions” was published in the Child Life Focus and provides readers with answers to questions to help identify research terms, understand methods, and incorporate research into a child life specialist’s daily practice (Carlton, et. al., 2014).

Recently, a child life specialist published a research article in the Child Life Bulletin that studied whether bubbles infused with essential oils would have higher anxiolytic effects for
pediatric patients in the pre-operative department than regular bubbles (Schuler & Hadayat, 2014). The study is a concrete example of well-written, quantitative research with the child life specialist taking an important role of Principal Investigator. Although this article did not prove significant findings between bubbles infused with essential oils and regular bubbles, the data of both interventions showed anxiolytic effects (Schuler & Hadayat, 2014). This article is an excellent example of useful research that can provide inspiration and confidence to other child life specialists hoping to begin conducting quantitative research.

Recent efforts are gaining momentum towards advancing research in the child life field. According to Dr. Turner, identifying individuals who are engaged in research may be an important step (2009) because in 2013, the CLC Research and Scholarship Committee published the results of a survey of child life program leaders regarding the “research needs and opportunities on the economic value of child life” (Child Life Council, 2013). The survey aimed to gain perspective on what previous research has been conducted and what research is in progress to prove child life cost effectiveness. Among 155 child life department leaders surveyed, the results showed only 12% of the departments had previously, or were currently participating in IRB approved research (Child Life Council, 2013). The child life department leaders were also asked what hospital settings they believed have the greatest need for research relating to showing the cost-effectiveness of child life. The results showed that there are many areas and interventions that child life leaders believe need cost effectiveness research. With 24 IRB approved research studies either completed, in progress, or in the planning stages, it is encouraging and exciting that child life specialists are looking towards a brighter future of research (Child Life Council, 2013).
To reinforce the trajectory towards increasing research, child life specialists need awareness of research models, methodologies, and designs in order to find one that works for their clinical practice (Crowell 2009). For child life specialists who have not received the academic training in research, an introduction of basic research training and workshops may help to spread research information. Finding a way to teach child life specialists about research can be done through a how-to research guide. This guide will be comprehensive, user-friendly, and accessible for child life specialists.

Recognizing that this guide is simply the beginning of a transition from research novice to active research investigator and that additional education, knowledge, and mentoring are needed to support child life specialists is an integral step. It is the goal of this writing to help bridge the gap between current child life practices and the expansion of the use of research as a means to advance the child life field and increase the many benefits the child life specialist delivers to pediatric patients and their families. I hope to provide a comprehensive and easy to follow how-to-guide that will overcome the intimidation and inspire students and professionals to embark on the important and exciting terrain of research.

**Rationale**

*How to Approach Research: A Guide for Child Life Specialists* is designed to provide a foundation for child life specialists who are interested in becoming involved in a research project but do not have experience. Many child life specialists lack academic support in research, therefore the research guide is written to identify research terminology, clarify research methodologies, understand research design, and think about ways to apply ongoing clinical work towards a research project.
Resources have been created to support child life specialists who are pursuing research, however many of these are in decentralized locations and may not be easily accessible for a child life specialist to gain a comprehensive understanding of how to become involved in research. Some resources use technical nomenclature that is difficult for beginning researchers to understand. Creating a research guide that is comprehensive, user-friendly, easy to follow, and uses appropriate terminology may help child life specialists to understand the research process better and encourage them to take on the challenge.

Similarly to how a child life specialist educates a child about the health care environment using developmentally appropriate language, the goal of this research guide is to explain research in a way that novice child life researchers can understand. By defining research terminology in simple ways, child life specialists can understand the material more easily. An alphabetized glossary is also located at the end of the research guide to find and define terms quickly.

A suggestion that has been made to help child life specialists become more involved in research is for them to participate in journal clubs as a way to communicate research activities and interests (Turner, 2014). Journal clubs can help child life specialists gain the skill of discerning quality of research by critically evaluating research papers in an educational and collaborative setting. In addition, reading journals more frequently can bring a reader up to date on child-centered care research that can be shared with the medical team, improve the quality of interventions by seeing what has been supported by research, familiarize the reader with design and technical approaches to research as well as inspire and motivate the reader to participate in research him/herself.

The resources that are available to child life specialists explain various evidence-based practice, qualitative, and quantitative studies. Understanding the different routes a child life
specialist can take towards participating in research activity helps them match their clinical style with a research style that works best for them.

Although there are many good research methods, the gold standard for reliable and generalizable research in any field is controlled randomized trials (Curry & Rosburg, 2009). There is a need to develop good resources for child life specialists who want to participate in this kind of research and thus the how research guide provides an outline to demonstrate how this kind of research can be conducted. It spans the entire process of developing a study from creating a question and defining variables, through explaining statistical analysis. The guide also uses examples that relate to child life services.

Included in the guide is information on Institutional Review Board (IRB) approval. Many child life specialists have yet to embark on IRB approved research. IRB approved research is important because of its credentials and the significance of keeping participants safe and their rights protected. The guide explains what the IRB is, how each hospital or institution may have their own IRB process, and what a typical process looks like. The intention of this research guide is to help child life specialists feel less intimidated and de-mystify the approval process.

To date little research has been done by child life specialists and it is difficult to find research resources that relate to the child life field. The research guide includes a list of common clinical settings, interventions, and outcome variables that specifically pertain to the child life profession. This could help a child life specialists think about their own experiences in their clinical setting and how it could serve as their foundation by becoming involved in a research project. Child life specialists need to realize that research is not a separate entity for the medical community only, but rather a component of clinical care that must be applied and used to strengthen the work that we, the child life specialists, do.
Conclusion

I am hopeful that the how-to research guide can help many students and child life professionals become involved in research activity. Although it does not cover the full extent of the matter, the how-to research guide is a needed step for the growth of research in the child life field. The guide aims to inspire many child life specialists to foster inquisitiveness and curiosity towards research. It is easily accessible for distribution to students and child life specialists. The research guide will be published in the Bank Street College of Education library accessible in both hard copy and online for other students to use. The guide will also be presented as part of a gap in service internship project, for a child life department in Brooklyn, New York.

While writing the research guide, I became more knowledgeable of the history of research for the child life field, the resources available, as well as the continued need for research growth in the field. During this process I also created a mock grant proposal for a sedation-free MRI study at my internship site. Although this study has not come to fruition, it was a helpful process for me to become familiar with participating in research as a child life specialist. Having experience with research in my undergraduate career as a neuroscience psychology student, I have understood research from a different discipline. My academic experience provided me with a foundation and interest to pursue the creation of the research guide. As I empathize with other child life specialists who are intimidated with research, I strongly agree that resources and changes should be made to provide further support.

It is my hope that the how-to research guide could be used on the Child Life Council website or posted in the Child Life Focus. There are many other ways that research could be supported to encourage future researchers such as developing a research curriculum for graduate
programs as an academic requirement to educate students in the field. Child life specialists who have already completed their academic requirements, may participate in an on-line research course. Making resources available in an educational setting guided by an experienced instructor will allow child life specialists to better understand and explore research.

Just like child life specialists are venturing beyond the walls of the hospital to schools, homes, and funeral settings, venturing into research will help with the expansion and growth of the field. As the child life profession matures, the bar will move from that of a burden of proof mentality, to one fostered through expanding applications and settings for the child life specialist that is rationalized by the beneficial research conducted by the growing child life specialist population.
References


Joint Commission on the Accreditation of Healthcare Organizations. Hospital Accreditation
Standards 2004. Oakbrook Terrace, IL: Joint Commission on the Accreditation of Healthcare Organizations; 2004


How to Approach Research
A Guide for Child Life Specialists
Welcome to How to Approach Research: A Guide for Child Life Specialists. This guide is meant to provide child life specialists with a comprehensive understanding of research so that they can utilize it to better understand and validate their interventions.

Due to the positive results and benefits from frequent use of research studies in the health care system, it is imperative for child life specialists to contribute to the interdisciplinary team and lead research themselves.

Research is the collection of information about a particular subject aimed to discover or interpret facts. Research can have many benefits to a child life specialist's career, the child life profession, and quality of patient care.

The goal of this guide is to help child life specialists feel more competent and excited to incorporate research into their practice!

Disclosure: The creator of this guide is in no way a "research expert" but understands the benefits of research for the growth of the field.
# Table of Contents

1. Research Related Activity
2. Challenges - What Research Means to You
3. Reading Research Articles
4. Evidence Based Practice - Quality Improvement
5. Methods of Research
6. IRB Approval
7. Research Design
8. Statistics
9. Clinical Application
10. Frequently Used Terms
In 2009, Dr. Joan Turner, a child life specialist, conducted a survey to find out about child life specialists participation in research related activity. The findings showed:

Table 1. Participation in Research Related Activity

The red bars clearly indicate more CLS surveyed have not participated in research related activities than those that have.
Challenges

*Lack of academic support*
- Few have had experience in undergraduate career and graduate careers because of lack of modeling and mentors from teachers

*Lack of time*
- Many CLS have busy patient loads and not much time for administrative/research opportunities

*Lack of funding*
- Research requires funding - many CLS don't have experience or knowledge in obtaining grants

*Lack of accountability*
- Many research responsibilities fall on managers or directors
- There are not yet requirements for CLS regarding research

*Lack of resources*
- Unsure where to find the proper resources

*Intimidation/Confidence Level*
- Some CLS may be fearful of pursuing research because of the perceived rigor of the work or lack of analytical thinking
It is useful to frequently read research articles to heighten your knowledge and advance the field of child life.

**What is a research article?**

- A paper written by authors who have collected and analyzed their own data, or analyzed data that had been collected from someone else.

- It builds upon previous research to show why the current research is important. It is comprised of new, original work, which has never been done before.

- Peer Reviewed Journals are the most reliable and valid sources because they have been evaluated by unbiased experts in the field.

**Finding research articles:**

- Databases that are child life applicable:
  - PubMed
  - PsycINFO
  - CINAHL Plus
  - MEDLINE

- Some of these require membership fees. You should ask your medical library if they have access to them.

- Child Life Council publishes articles on Child Life News Monthly located on www.childlife.org

**Applying to Practice:**

- Stay current with the most up-to-date research.
- Transfer pertinent information to medical team.
- Discern quality of research studies.
- Inspire you to create your own research study.
- Find research to support child and family-centered care.

---

**Literature Review**

**What has been done before?**

A good literature review should:
* Describe work done by other scholars, not just author of the paper.
* Incorporate Peer Reviewed Journals.

**Overall Goal:** Provide reader with summary of previous research findings to highlight questions that remain unanswered and require additional research.

**Research Question**

**What are they studying?**

The research question should be original, clearly stated and answered by the end of the article.

Frequently, authors will state the research question as a hypothesis and predict what they think will happen and test it to see if it holds true.

**Example:** To determine the effect of child life intervention on the success rate, anxiolytic effects, and image quality of pediatric patients undergoing sedation-free MRIs.

**Data**

**Who is being studied?**

Should provide a good description of the data used in the analysis.

Some important aspects of the data that require consideration are:

- **Sample Size:** The number of participants in the study, used to represent a bigger population. The smaller the sample size, the more difficult it will be to conduct analyses and the less reliable and generalizable these analyses will be.
- **Representativeness:** The description of the data should help clarify whom the authors hope to represent and describe in their sample.
- **Descriptive Statistics:** Authors should use: means and standard deviations to describe their sample.
Measures

How each variable used in the analysis is measured and defined:

How to define variables:
Example: a study is measuring a child's anxiety level, how is this defined?
- Are they using a face scale?
- A parent survey?
- Cortisol levels?

- Are they using several items or a single item?
- Did they create their own measure, and if so, how did they do it?

*If they use an assessment that has already been developed and tested, they simply cite that it is widely-used and previously validated.

Pre-test/Post-test methodology can be used before and after an intervention to see if any changes have occurred. Measures can also see if there is a difference between groups. Example: Measuring cortisol levels before or after child life preparation.

Methods & Results

What did they do and what did they find?

METHODS
Methods are different ways to design and collect data.

Some different methods of research:
Qualitative
Quantitative
Mixed Method

RESULTS
After collecting and analyzing data, the results show you what the methods support. Results can come in various forms:
Mean: the average value of measurement regarding each group.

Standard Deviation: How variables are distributed around the mean.

P-Value: a number representing how trustworthy the results are.

Conclusion

What does it all mean?

At the end of a research article, the authors summarize their findings from the analyzed results and offer interpretations.

Sometimes the analyzed results are not significant and the author would have to explain why this may have happened.

The authors mention any limitations that may have impacted the findings and conclusions. Example: The sample size was too small to generalize for a population.

The conclusion should answer questions such as:
• What can we take away from this?
• What still remains to be learned?
• What next steps are needed for research?

Journal Club Ideas:

To start a journal club ask other child life specialists or members of the interdisciplinary team if they would like to join. This could increase skills at reading journals and knowledge of research. A resource for relevant child life journals are published in the Child Life News Monthly. Having a critical eye: To help discern quality of research look for: bias towards an outcome, significant findings, and whether the article has been peer-reviewed.

Challenge:
Could you set a goal to read 1 article a week?
Evidence Based Practice

Definition
Supporting interventions through data collection and evidence.

Evidence Based Practice + Clinical Practice + Patient Preference

Difference of Research
EBP is a little less strenuous as you can take the interventions that you use and format it to meet the criteria without IRB approval. It allows a practitioner to be flexible with the approach if it does not work for the patient.

*Very individualized

Sources for Creating EBP
- Opinions of authorities
- Reports of expert committees
- Systematic Reviews
- Randomized Controlled Trials
- Theory and humanistic approaches that are grounded in qualitative & quantitative research

Child Life Council Resources
VISIT THE CHILD LIFE WEBPAGE (www.childlife.org):
Then Click Resource Library -> Then Click EBP Statements:
* CLC Position Statement
* Child Life Assessment
* Therapeutic Play in Pediatric Health Care Settings
* Preparing Children and Adolescents for Medical Procedures
* Practice Model
* Steps to Utilize
* Also download the Modules for more support with creating an Evidence-Based Practice Statement

Where to find EBP
The National Guideline Clearinghouse: www.guideline.gov
Cochran Collaboration or Library: www.cochrane.org
The Joanna Briggs Institute: www.joannabriggs.edu.au
TRIP (Turning Research Into Practice) Database: www.tripdatabase.com

Check out these EBP resources!
Quality Improvement is a frequently used research method for child life specialists.

**Definition**

Aimed at improving internal processes while the goal of conducting research is to generate more generalizable knowledge for broader application.

**Difference of Research**

No IRB Approval necessary. QI involves a small test of change designed to bring about swift improvement, while research uses systematic methodology, rigorous data collection and statistical analysis.

**How to use**

QI may trial a change with two patients before deciding to adopt or adapt the process, while a research project must follow the research protocol meticulously. If changes are needed, they need to be approved by IRB.
A research study can use two methods: Qualitative or Quantitative. Some combine both methods and are called "Mixed Method"

**QUALITATIVE**

**Why**
- To gain an understanding of underlying reasons and motivations
- Gives children, families, and healthcare workers an additional means to be heard as their specific experiences lead to further insight and development

**Common Methods**
- Phenomenology
- Ethnography
- Grounded Theory
- Case Study

**Data Collection**
- Unstructured techniques: Open-ended Interview

**Data Analysis**
- Non-statistical

**Outcome**
- Exploratory and/or investigative. Findings are not conclusive and cannot be used to make generalizations about the population of interest. Develop an initial understanding and sound base for further decision making.

**QUANTITATIVE**

**Why**
- To quantify data and generalize results from a sample to the population of interest
- Can usually be replicated or repeated, given its high reliability

**Common Methods**
- Descriptive
- Correlational
- Cause-Comparative
- Experimental

**Data Collection**
- Structured techniques: Rely on random sampling and structured data instruments

**Data Analysis**
- Statistical data is used

**Outcome**
- Used to recommend a final course of action. Produce results that are easy to summarize, compare, and generalize.
Common methods of Qualitative and Quantitative Research

**QUALITATIVE**

**Phenomenology:**
Seek to capture the lived experience of individuals and the perceptions of their own presence in the world: *What does it mean to live with a certain illness?* Done through taped, unstructured conversations and later reflection on both the data obtained and the researcher’s personal experience.

**Ethnography:**
Typically utilized to explore cultural groups. May be guided by the general question: *What are the patterns of behavior implicit within this culture?* Researcher defines the selected setting or field and all data is collected within this natural setting.

**Grounded Theory:**
Questions with a focus toward examining and understanding processes designed to generate and test theory. Researcher actively collects, analyzes, synthesizes, and integrates the data to capture the emerging theory that serves to explain the process involved.

**Case Study:**
A descriptive, exploratory, or explanatory analysis of a person, group or event.

**Prospective:** Subjects are recruited then studied looking at differences.

**Retrospective:** Subjects chosen, then data is collected on their past experiences.

**QUANTITATIVE**

**Descriptive:**
Used to describe characteristics of a population. Aims to find out what the characteristics of the population are being studied. Usually follows explanator research. Has a low requirement for internal validity. Cannot be used explain a causal relationship, where one variable affects the other.

**Correlational:**
Tests for statistical relationships between variables. A researcher may hypothesize that there is a positive or negative correlation between two variables. However, it is important to remember, correlation does not imply causation.

**Cause-Comparative:**
Attempts to determine cause and effect and is used when independent variables cannot be examined using controlled experiments. It is a common design in educational research studies and is not as powerful as experimental designs.

**Experimental:**
Limit bias and designed to test the effect of a planned intervention. Determination of the size of the trial (number of subjects in each group) is critical and depends on the incidence of the outcome measure in the control population as well as the effectiveness of the intervention.
Although the paperwork is lengthy, getting IRB approval is feasible and is put in place to ensure the safety of participants.

**What is the IRB?**

IRB stands for Institutional Review Board. It is also known as independent ethics committee or ethical review board. It is comprised of at least five members from different professions that have experience, expertise, and diversity to make an ethical decision. The IRB ensures that the research study conducted is not compromising the rights or harming any of the participants.

**In Your Institution**

Many institutions may have their own IRB. This is comprised of physicians, people from the community, and experts in the field. Usually you can find out who is on the IRB at your hospital by checking out your hospital’s website. It is a good idea to meet with the IRB to get to know the people approving your study.

**Steps for Approval**

To become approved for an IRB you need to follow these steps:
1. Complete an IRB Training Course
2. Familiarize yourself with IRB’s purpose and procedures
3. Review key portions of proposed research
4. Consult IRB staff member in charge of reviewing protocols to ask questions, receive clarification on any issues before submitting protocol.
5. Obtain and complete an IRB protocol and related forms and applications
6. Submit your application
7. Receive either an immediate approval or request for clarifications.
8. Begin work!
Creating a research study involves following steps.

**Research Question**

A research question identifies the specific objectives the study or paper will address.

- **Feasible**: Adequate number of subjects, technical expertise, affordable in time and money, manageable in scope.
- **Interesting**: Getting the answer intrigues investigator, peers, and community.
- **Novel**: Confirms, refutes or extends previous findings.
- **Ethical**: Amenable to a study that IRB will approve.
- **Relevant**: To scientific knowledge, clinical health policy, future research.

**Hypothesis**

A hypothesis is what you think the results of the study will show.

Developed from a good research question, sampling strategy, intervention, comparison and outcome variables.

- **Null Hypothesis**: Statement that the things you are testing are not related and your results are the product of random chance events.
- **Alternative Hypothesis**: The claim you are testing.
**Variables** are anything that can change or effect the results of a study. Considering variables helps to understand differences.

| Controlled          | The things that stay the same. They keep the experiment fair.  
| Example: Patients having the same procedure |
|---------------------|----------------------------------------------------------------|
| Independent         | The variable that is manipulated by the experimenter. The thing you change.  
| Example: Intervention vs. No Intervention |
| Dependent           | The variable that is measured by the experimenter.  
| Example: Anxiety levels of patient |
| Extraneous          | An extra variable that may or may not affect the results.  
| Example: Ethnicity of patient |
| Confounding         | An extraneous variable that affects the results.  
| Example: Anxiety level of parent |
Statistics are used to determine the sample size, validity, and confidence level of the study.

DETERMINING SAMPLE SIZE

When you are determining how many participants you will need in your study consider:

- The larger your sample size (n), the more sure you can be that the results of the study truly reflect the population.

- The size of the sample size coincides with the size of the population. The size of the sample size coincides with the size of the population.

- Population may be the number of patients on an inpatient unit or the number of patients with a certain chronic illness.

Sample Size Calculators:
U.S. Department of Health and Human Services, Health Resources and Services Administration website has a link to a sample size calculator.

Confidence Level:
Tells you how sure you can be. The probability that the value of a parameter falls within a specified range of values.

Confidence Interval:
The plus-or-minus figure that gives a range of estimated values.

Population:
How many people are in the group your sample represents? If the population is >500 or unknown, the same statistical number is used.
STATISTICAL INFORMATION

Software: sometimes it is necessary to report which software you used. Example: Biostat, SPSS, R-Project

Summarize: be consistent with how the data is summarized. Example: Mean, percent, etc.

How you report measures of variability
Example: SD (standard deviation), SEM (standard error of mean), Confidence Levels

Data transformations: To make it easier to visualize the analyzed data
Example: To correct for normal distribution or equalize variance

Statistical tests: Tests the probability that your Null Hypothesis is valid. It compares the two or more means (averages) that you get from each separate group in your research study. Here is a list of different types of statistical tests:
1. Standard t-test
2. Paired t-test
3. One-way ANOVA (Analysis of Variance)
4. Two-way ANOVA
5. Linear Regression

STATISTICIAN

A statistician is a person with expertise in theoretical or applied statistics. He/She will help you to:
* Determine the sample size
* Analyze the data collected

The hospital you work in may have a statistician, or you may need to hire a statistician.
CLINICAL SETTING

Top 5 most commonly mentioned clinical settings in need of child life research related to cost effectiveness:

- Radiology/Diagnostic Imaging
- Surgery
- Emergency Department
- Procedures Unit/Procedural Area
- Inpatient

Areas that are most conducive:

* High patient volume need fast turn-over
* Areas that rely on sedation use
* Inpatient unit due to focus on discharge

INTERVENTIONS

Top 5 most commonly mentioned interventions provided by child life specialists in need of research related to cost effectiveness:

- Preparation
- Procedural Support/Distraction
- Diagnosis Education
- Normalizing Play/Activities/Events/Playroom
- Medical Play

OUTCOME VARIABLES

Top 5 most commonly mentioned variables to be studied in relation to research related to cost effectiveness:

- Sedation use
- Staffing time and costs
- Compliance
- Anxiety
- Length of stay
There are many measurement tools already available that child life specialists can apply to their research studies.

<table>
<thead>
<tr>
<th>Sedation Use</th>
<th>Staffing Time/Cost</th>
<th>Compliance</th>
</tr>
</thead>
</table>
| Was the medical procedure able to be completed:  
*With anesthesia  
*Without anesthesia  
Easily Measureable | *How many staff are present  
*How much time did it take  
*CLS presence may reduce number of staff involved leading to reduced cost | Was the medical procedure able to be done with:  
-Less holding  
-Less fighting  
-More willingness |

<table>
<thead>
<tr>
<th>Length of Stay</th>
<th>Anxiety</th>
<th>Comfort/Pain</th>
</tr>
</thead>
</table>
| Did medical education, therapeutic activities, medical play, or recreational activities aid in:  
*Increasing mobility  
*Reduce stay  
*Discharge support | *Cortisol Levels  
Vital Signs  
*modified Yale Preoperative Anxiety Scale  
*Parent survey  
*FIS (facial image scale)  
*Corah’s Dental Anxiety Scale  
*Observation Scale of Behavior Distress  
*State-Trait Anxiety Inventory for Children | *Comfort Scale  
*The McGill Pain Questionnaire  
*Oucher Assessment tool  
*FACES Scale |

(2, 3)
What Research Means to You

Journal Club
You may be inspired to start a journal club or simply begin looking at more research articles to defend child and family-centered care.

Collaborate
You may want to join a research project with other members of the interdisciplinary team who are more experienced in research.

Conduct Your Own Research
You may be inspired to start your own research project whether it be qualitative, quantitative, or a mixed method approach.
Abstract
A brief summary of the research study describing the objective, its methodology, findings, conclusions, or intended results.

Clinical Trial
A research study using human subjects to evaluate the effect of intervention or exposures on biomedical or health-related outcomes.

Coefficient
Estimated Effect. Association between two variables ranging between -1 and 1.

Confidence Interval
The plus-or-minus figure that gives a range of estimated values.

Confidence Level
The probability that the value of a parameter falls within a specified range of values.

Cross Sectional Study
An observational study that involves data collection from a population at one specific point in time.

Data
Facts and statistics collected together for reference or analysis.

Dependent Variable
A variable whose value depends on changes made to another variable.

Ecological Studies
Can be used to make a comparison of trends in a condition to possible contributing factors.

Ethnography
Typically utilized to explore cultural groups. May be guided by the general questions: What is currently going on within this area? or What are the patterns of behavior implicit within this culture? Researcher defines the selected setting or field and all data is collected within this natural setting.
**External Validity**
The extent to which the results of a study can be generalized to other situations and to other people.

**Generalizability**
Ability to use results from a study as a representation of a bigger population.

**Grounded Theory**
Questions with a focus toward examining and understanding processes designed to generate and test theory. The researcher actively collects, analyzes, synthesizes, and integrates the data to capture the emerging theory that serves to explain the process involved.

**Human Subjects/Participants**
People who participate in a research study.

**Hypothesis**
A supposition or proposed explanation made on the basis of limited evidence as a starting point for further investigation.

**Independent Variable**
A variable whose variation does not depend on another and is adjusted by the experimenter.

**IRB**
Also known as an independent ethics committee or ethical review board, is a committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans.

**Limitations**
Characteristics of methodology or design that may have affected the interpretation of your results.

**Linear Regression**
An approach for modeling the relationship between dependent variable and one or more explanatory variables.
Literature Review
A select analysis of existing research which is relevant to your topic.

Mean
The average. Calculated by adding all of the values together, then dividing by the number of values.

Null Hypothesis
The assertion that the things you were testing are not related and your results are a product of random chance events.

Peer Reviewed Journals
Research articles analyzed by experts in the field that determine the quality of the work and whether it should be revised.

Phenomenology
Seek to capture the lived experience of individuals and the perceptions of their own presence in the world: What does it mean to live with a certain illness? Done through taped, unstructured conversations and later reflection on both the data obtained and the researcher’s personal experience.

Population
A large collection of individuals or objects that is the main focus of the research question.

Primary Data Analysis
Data collected by the investigator conducting the research.

P-value
A number representing how trustworthy the results are.

Principal Investigator (PI)
The lead scientist for a research project. “Head of the laboratory” or “research group leader”.
Protocol
A written plan that describes the clinical-trial activities. Primary elements include scientific background, purpose and objectives of the study, a description of the study design, and the statistical plan.

Quantitative
Relating to, measuring, or measured by the quantity of something.

Qualitative
Aim to gather an in-depth understanding of human behavior and the reasons that govern such behavior.

Quasi-Experimental
Nonrandomized, pre-, and post-intervention studies. They are often employed in outbreak situations or quality improvement interventions.

Randomization
The process of assigning groups to a treatment or control condition randomly.

Research Assistant
A researcher employed, often on a temporary contract, by a university or a research institute, for the purpose of assisting in academic research.

Research Coordinator
Responsible for the daily clinical trial activities that include supporting recruitment, study visit activities, and documentation. May be nurses, medical technologists, or respiratory therapists.

Research Question
A brief question that helps direct your efforts to collect, critically read, and evaluate your sources.

Research Site
Refers to the location where the research is conducted. An academic research center is an institution where patients receive medical care and clinical trials are conducted.
**Sample Size**
An important feature of an empirical study in which the goal is to make inferences about a population from a sample. A small part or quantity intended to show what the whole is like.

**Secondary Investigator**
Additional investigators involved in the study.

**Secondary Data Analysis**
The use of data that was collected by someone else for some other purpose.

**Standard Deviation**
A quantity calculated to indicate the extent of variation for a group as a whole.

**Standard of Error Mean**
The standard deviation of the sampling distribution of a statistic.

**Statistician**
An expert in the preparation and analysis of statistics.

**Statistical Software**
Computer programs for statistical analysis that uses algorithms (step-by-step procedures) for calculation.

**Statistical Tests**
Tests the probability that your null hypothesis is valid.

**Validity**
The quality of being logically or factually sound.


