

FERP

Fetal Echocardiography Referral Program

The Dissemination of Guidelines Aimed to Improve Provider Knowledge

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DEDICATION

I would like to dedicate the entirety of my doctoral studies, research and completed work to my incredible family. To my husband Kevin who has stood by my side through some of the hardest moment's life has offered us and some of the greatest as well. I would not be who I am today without you and I could not have accomplished my goals and dreams without you by my side. To our 4 beautiful girls who impress me daily with their incredible heart, grace, strength, intelligence and resilience, you teach me the joy and preciousness of this life daily and have been my biggest accomplishment. I also want to recognize my parents who instilled in me not only a continued thirst for learning, and the value of education but the fundamental idea of giving, so to that end I strive to be better, learn more so I hopefully am able to contribute more to my patients, their families and the improvement of healthcare as a whole.



Abstract

Although clinical practice guidelines do exist regarding fetal echocardiography referrals, these guidelines are often not utilized in practice due in part to lack of provider knowledge. The primary purpose of this six-week Quality Improvement (QI) Project was to increase the knowledge of obstetrical providers regarding the guidelines for fetal echocardiography referrals. A three-phase intervention project using a non-experimental descriptive design methodology was implemented, employing both pre- and post-project surveys to procure a convenience sample of obstetrical providers within a fifty-mile radius of a specified southern California zip code. A paired-samples t-test was used to evaluate the statistical significance of pre- and post-project obstetrical provider scores. Study findings indicated positive correlation between the use of educational intervention, implemented by an advanced-practice nurse utilizing a multi-modal approach, and increased provider knowledge on Fetal Echocardiography Guidelines.

Keywords:

Evidenced-based Practice, Fetal Cardiology, Fetal Echocardiogram, Clinical Practice Guidelines,

Stetler Model

Fetal Echocardiography Referral Project (FERP)

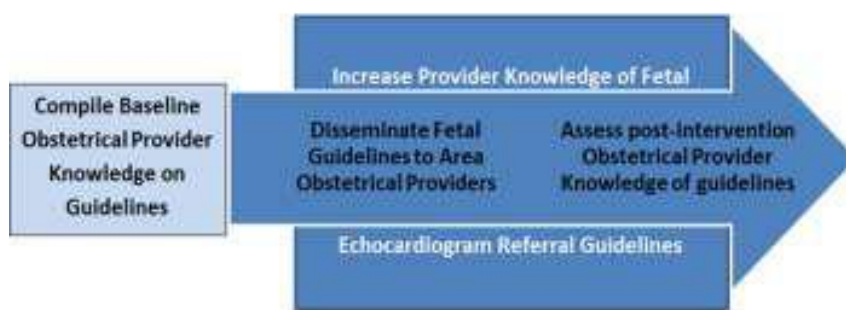
Congenital heart disease (CHD) is the leading cause of infant death, with an estimated annual incidence of about nine per one thousand live births (AHA, 2010). With this high mortality, it is surprising that fetal and newborn screening is not routinely done when well-established clinical practice guidelines to identify at-risk obstetrical patients are available (Cameron, 2010). Three out of five women who have given birth to a child with CHD were never tested for the defect during their pregnancy (Cameron, 2010). Advanced practice nurses (such as midwives or family practice nurse practitioners) who provide care for the obstetrical population play a crucial role in the care of these patients, and therefore have a direct responsibility for the knowledge of these best practice guidelines.

A nurse practitioner initiated this project due to events that triggered investigation into a disproportionate number of newborns being diagnosed with CHD at birth in the tertiary care practice setting, despite the fact that mothers had a known risk and no referral for fetal echocardiogram was made. Fetal echocardiogram is a medical diagnostic tool for which each member of the healthcare team must advocate as a consistent standard of care.

Advances in fetal echocardiography have led to increasing numbers of infants being diagnosed prenatally as having CHD. Optimal care of infants who have significant CHD begins before delivery, with prenatal management and care planning, and continues with skilled resuscitation in the delivery room and subsequent timely admission to an intensive care unit. Prenatal diagnosis allows for coordination of care surrounding delivery and during the early postnatal hours (Johnson, 2005). An alarming number of newborn infants are diagnosed at delivery, and many children receive the CHD diagnosis as late as in their teens. Preparation for early care of the infant is critical and for this, caregiver knowledge of prenatal diagnosis is important. The first

question is to determine the provider's knowledge of fetal echocardiogram referral guidelines for screening and referral. A three-phased approach consists of 1) obtaining baseline provider knowledge via a pre-intervention survey; 2) providing well-established guidelines with supporting evidence to participating providers; and 3) implementing a post-intervention knowledge survey (Figure 1). This survey assesses change in the participating obstetrical providers' level of knowledge of fetal echocardiography referral guidelines.

Figure 1. Strategy to increasing obstetrical provider's knowledge of fetal echocardiography referral guidelines.

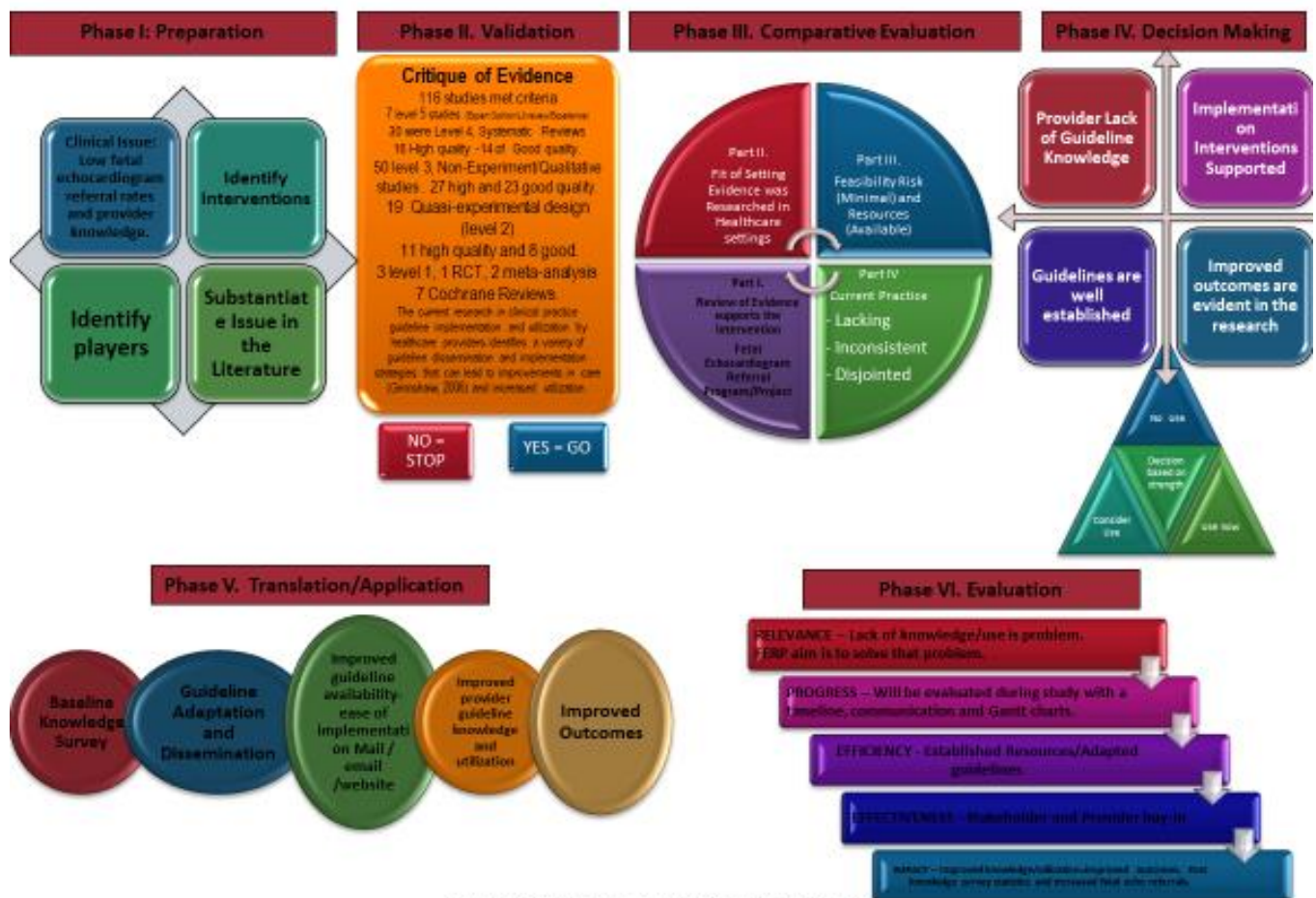


Translational Framework

The Stetler's Model of Research Utilization to Facilitate Evidence-Based Practice served as a framework to guide the synthesis of existing research on fetal echocardiography referral clinical practice guidelines and provider knowledge. This stepwise framework also aided the information gathering process, as it provided guidance for identification of gaps in the extant knowledge, as well as in areas in need of strengthening or further evaluation. Finally, the model facilitated transforming the understanding of the evidence provided by the extant literature into practice through the Fetal Echocardiography Referral Project (FERP). The six phases of the model (Figure 2) were followed in this project in order to ensure that the program would be effective, valid and appropriate for the setting for which it was aimed. The six phases are sequential steps, in which each step's results are

used to inform the next. The first phase focuses on preparation or problem identification, and is followed by validation of the problem, which is a four-part comparative evaluation phase that reviews the evidence, ensures that the program is fit for the setting in which the change would be applied, and verifies the feasibility of that change in the light of the current practice. The process continues with the decision-making phase, which leads into the translation, application and the evaluation phase (Stetler, 2001).

Figure 2. Six-Phase Modified Stetler’s Model of Research Utilization to Facilitate Evidence-Based Practice



A Translational Approach to Research Utilization.
Adapted from Stetler’s Model of Research Utilization. Sudsawad, P. (2007). (Sarah Ann Keil Heinonen)

Review of the Literature

Fetal echocardiography referral guidelines and provider knowledge of established guidelines were reviewed.

Fetal echocardiography referral guideline indicators

Fetal echocardiography referral guideline indicators specify baseline knowledge necessary for appropriate referrals for fetal echocardiography. A comprehensive search in Pubmed, Medline Plus, CINAHL Plus, Embase, Up-To-Date and the Cochrane Library were completed. Fetal Echocardiography Practice Guidelines, Sonography, Fetal Cardiology, and Congenital Heart Disease/Defects were keywords used in the database search from 2000-2010. Relevant guidelines from both organizations and large healthcare insurance providers were also reviewed to include their fetal echocardiogram guidelines for reimbursement.

Nine published fetal echocardiography guideline sources were identified; maternal, fetal and familial were the three main indicator categories identified in the literature with one subsequent follow-up indicator category. All reviewed documents supported the use of fetal echocardiography referral guidelines in obstetrical provider practice to improve overall quality of patient and family care (*Appendix A*). All reported and published fetal echocardiography referral guideline indicators were reviewed and are reported in Table 1 and 2.

Table 1. Fetal Echocardiography Referral Guideline Indicator Tables

GUIDELINE SOURCE	Family History	Metabolic Disorders (IDDM/PKU)	Teratogens Exposure	Exposure to PGE synthetase inhibitors	Viral infections during pregnancy	Autoimmune diseases	Familial inherited disorders	IVF	Previous child w/CHD	Syndromes (e.g. VCF, Noonan's, Turner's)	Abnormal Amnio / Chromes	Abnormal Fetal Heart Rhythm
American Society of Echocardiography (ASE)	X	X	X		X	X	X	X	X	X	X	
American Heart Association (AHA)	X	X	X		X	X	X		X		X	X
International Society of Ultrasound Obstetrics and Gynecology (ISUOG)	X	X	X		X	X			X		X	X
AETNA Insurance	X	X	X	X		X		X	X		X	X
American Institute of Ultrasound Medicine (AIUM)	X	X	X			X	X	X	X		X	X
KAISER Insurance	X	X				X			X	X	X	X
American College of Cardiology (ACC)	X	X	X			X			X		X	X
Blue Cross Blue Shield Insurance	X	X	X		X	X	X		X	X	X	X
Up-To-Date	X	X	X	X	X	X			X	X	X	

Table 2. Fetal Echocardiography Referral Guideline Indicator Tables

GUIDELINE SOURCE	ICIS Intracytoplasmic Sperm Injection	Abnormal OB ultrasound / Extracardiac abnormalities	Fetal Hydrops / Polyhydramnios	Multiple Gestations	Increased nuchal translucency thickness	Abnormal Fetal Situs	Monochromic Twins (with or without twin-twin transfusion syndrome)	IUGR	2 Vessel umbilical Cord	seizure disorder/ Anti seizure med exposure
American Society of Echocardiography (ASE)		X	X	X	X					X
American Heart Association (AHA)		X	X							X
International Society of Ultrasound Obstetrics and Gynecology (ISUOG)		X			X					X
AETNA Insurance	X	X	X						X	X
American Institute of Ultrasound Medicine (AIUM)		X	X		X		X			X
KAISER Insurance		X			X					
American College of Cardiology (ACC)		X		X						
Blue Cross Blue Shield Insurance		X	X					X		
Up-To-Date		X	X		X	X	X			

Provider knowledge

Literature from 2000-2010 addressing provider knowledge using the keywords, evidence-based practice, clinical practice guidelines, barriers to guideline utilization and implementation was reviewed. Electronic databases included Pubmed, Medline Plus, CINAHL Plus, Embase, Up-To-Date and the Cochrane Library. Many challenges were reported in the literature with regard to clinical practice guidelines; but for the purposes of this review and ensuing project, provider knowledge was the primary focus. Thirty-nine studies (*Appendix B*) met the inclusion criteria for the systematic review.

The literature review indicated that a variety of guideline dissemination and implementation strategies exist to increase knowledge, with the potential to lead to improvements in care (Grimshaw, 2006). Data is mixed regarding the most effective strategy for guideline dissemination and implementation (Grimshaw, 2006). According to Francke (2008), compliance with clinical practice guidelines is a complex issue and includes a number of barriers. The literature overall reported five consistent barriers to guideline implementation: lack of knowledge, provider time constraints, lack of support, personal beliefs and guideline presentation (dissemination). Although the literature supports the approach of careful tailoring of implementation interventions to the barriers (Graham, 2004), the lack of feasibility and generalizability within that approach makes it less favorable. Many authors additionally favor a multi-pronged or multifaceted approach to dissemination of practice guidelines, stating that such strategy would assist in acquiring significant improvements in change in knowledge, practice, and patient outcomes (Medves 2009, Beck 2002, Lugtenberg 2009, Ockene 2000) (*Appendix B*).

Lugtenberg (2009) and Ockene (2000) refer to the need for knowledge of the guidelines with transparent evidence and applicability to support guideline implementation in practice. Transforming

evidence into practice and implementing clinical guidelines are dependent on practitioner knowledge of the guidelines. This first-step thought process that guided the choice of knowledge as the focus barrier for this project. In concert with disseminating knowledge in the form of guidelines but also in the form of evidence are the ideals from which this project's aims stemmed. It is hoped that their increased knowledge of guidelines will lead to the optimization of outcomes. With this goal, the FERP was designed to evaluate the baseline knowledge and effectiveness of a basic educational intervention as a means of increasing obstetrical provider knowledge on fetal echocardiogram referral guidelines (FERGs).

Utilizing a systematic approach to review the reported dissemination procedures in the literature, tables were created to evaluate the majority rule regarding reported interventions to approach barriers to use of guidelines in practice (*Appendix B*). Although mixed results were reported with all interventions, it was noted in the reviewed articles that an Educational Approach was reported in 29 of the 39 articles being the highest reported of interventions. Additionally, a multifaceted strategy intervention was reported as the majority in 21 of the reviewed articles, with a higher report rate than either specifically identifying barriers and individualizing, or a single strategic approach. It was this evidence that guided the creation of a three-phase, prepackaged educational approach to the FERP intervention via a mailed survey to reach as many providers in the rural areas, where electronic means for dissemination may not be an option.

Methods

Participants and sample selection

Participants were obstetrical providers in an online insurance database and practice within a fifty-mile radius of a southern California tertiary care institution. Five hundred and twenty-four providers were identified. Gender, practice specialty, time in practice, practice affiliation (private or

hospital-affiliated) and some referral practices (annual referral rates and type of provider referred to) associated with these providers were obtained and are presented in Table 3.

Survey development

The survey instrument was developed using content in the fetal echocardiography guidelines and published resources specific to survey question development (*Appendix C and D*). Questions were reviewed by experts in the field of fetal cardiology for face validity. Experts were asked to assess question relevance, clarity, and structure. This process resulted in a twenty-item survey.

Procedures

Project approval was obtained from both affiliating IRBs prior to implementing the three phases. In Phase One, a twenty-question knowledge survey accompanied by an introduction letter and request to participate was mailed via U.S. postal service. Reminder cards were mailed, and follow-up phone calls completed thirteen days after initial mailing (*Appendix E*). In Phase Two, after the completed knowledge survey was returned, fetal echocardiography referral guidelines, review of the literature abstract, and a thank-you letter for their continued participation were mailed to participants (*Appendix F*). In Phase Three, the post-knowledge survey and a thank-you letter were mailed. Reminder cards were sent, and follow-up phone calls completed twelve days after survey packets were mailed (*Appendix G*).

Data analysis

Survey data were analyzed utilizing SPSS (PASW) version 18.0. The descriptive statistics of the demographic data are reported. Only complete pre- and post-survey data were analyzed using a paired t-test. Descriptive statistics are also included.

Power analysis/sample size

Post hoc power analysis was completed utilizing an online tool. Based on the paired t-test results, a power of 1.0 with an alpha of 0.05 was determined. Additionally, effect size for this project was calculated using Cohen’s d, resulting in 1.2, which constitutes a very large effect size. (Cronk, 2006). Sixty-five participants were calculated for this effect size.

Results

A total of sixty-five out of five hundred and twenty-four (Table 3) invited participants completed both pre- and post-intervention knowledge surveys for an overall provider response rate of 12%. Within each identified specialty, the general obstetrician-gynecology (obgyn) group had the highest response rate, at 7%, with the other five categories having a 1% or less response rate individually (Table 3). Among the contacted participants, one hundred and eighteen responded to the pre-knowledge survey (22% response rate) and sixty-five returned the post-knowledge survey.

Table 3. Respondent (n=524) Demographic Characteristics

Respondent Characteristics						
(n=524)	Provider Type					
Characteristic	OBGYN-General (n=253)	Midwives (n=17)	Family Nurse Practitioner (n=45)	OB-Maternal Fetal Medicine /Perinatology (n=157)	MD - Family Practice (n=13)	OB - Repro- Endoc (n=39)
Provider Gender						
Male	133	-	4	138	8	34
Female	120	17	41	19	5	5
Spanish Speaking						
Yes	70	6	14	52	5	9
No	183	11	31	105	8	30
Practice Type						
Private Practice	90	6	8	5	6	19
Hospital Affiliated	163	11	33	14	7	20
* Participation numbers did not support statistically significant findings amongst demographic variables.						

Table 4. Respondent (n=118) Demographic Characteristics

Respondent Characteristics (n=118)							
Characteristic	Provider Type						
	OBGYN-General (n=51)	Midwives (n=6)	Family Nurse Practitioner (n=15)	OB-Maternal Fetal Medicine /Perinatology (n=29)	MD - Family Practice (n=4)	OB - Repro-Endoc (n=13)	
Time in Practice (years)							
0-5	5	-	3	6	1	2	
6-10	18	2	4	2	2	2	
11-15	6	1	6	7	-	3	
16-20	7	2	1	6	1	3	
> 20	15	1	1	8	-	3	
Provider Gender							
Male	45	-	6	21	3	11	
Female	6	6	9	8	1	2	
Spanish Speaking							
Yes	34	2	5	11	2	3	
No	17	4	10	18	2	10	
Annual Referral Rates							
0	10	-	2	4	-	3	
1-5	15	1	3	10	-	2	
6-10	16	2	4	9	3	5	
> 10	10	3	6	6	1	3	
Provider Referral Type							
High Risk OB	26	3	5	10	2	1	
Diagnostic Center	14	1	2	5	-	2	
Pediatric Cardiology	6	2	5	8	2	6	
Other-unspecified	5	-	1	6	-	4	
Deciding Factor for Referral							
Affiliation	21	3	7	8	-	1	
Insurance	10	1	3	6	1	6	
Reputation	11	1	2	8	1	4	
Personal Preference	6	-	2	5	2	2	
All of the above	3	1	1	2	-	-	
Practice Type							
Private Practice	19	2	7	8	2	5	
Hospital Affiliated	32	4	8	21	2	8	

* Participation numbers did not support statistically significant findings amongst demographic variables.

Table 5 summarizes the demographic and practice characteristics of the project provider participants (n=65). In a general obgyn practice, respondents were predominantly male, with a designated hospital affiliation. Annual referral rates for this group were highest in the 1-5 and 6-10 year categories, and the highest referrals were to the high-risk obstetricians.

Table 5. Respondent (n=65) Demographic Characteristics

Respondent Characteristics							
(n=65)		Provider Type					
Characteristic		OBGYN-General (n=37)	Midwives (n=6)	Family Nurse Practitioner (n=5)	OB-Maternal Fetal Medicine /Perinatology (n=9)	MD - Family Practice (n=4)	OB - Repro- Endoc (n=4)
Time in Practice (years)							
(n=8)	0-5	4	-	1	2	1	-
(n=23)	6-10	16	2	2	1	2	-
(n=10)	11-15	4	1	2	2	-	1
(n=11)	16-20	4	2	-	2	1	2
(n=13)	> 20	9	1	-	2	-	1
Provider Gender							
(n=48)	Male	34	-	-	7	3	4
(n=17)	Female	3	6	5	2	1	-
Annual Referral Rates							
(n=8)	0	6	-	-	1	-	1
(n=17)	1-5	11	1	-	4	-	1
(n=23)	6-10	11	2	2	3	3	2
(n=17)	> 10	9	3	3	1	1	-
Provider Referral Type							
(n=32)	High Risk OB	20	3	3	4	2	-
(n=13)	Diagnostic Center	11	1	-	1	-	-
(n=16)	Pediatric Cardiology	4	2	2	3	2	3
(n=4)	Other-unspecified	2	-	-	1	-	1
Practice Type							
(n=23)	Private Practice	13	2	1	3	2	2
(n=42)	Hospital Affiliated	24	4	4	6	2	2
* Cell size precludes tests of significance by provider type.							

Table 6 summarizes the results of the paired-samples t-test that was conducted to compare the mean pre- and mean post-knowledge survey scores. Participant scores were normally distributed, and no missing values were noted for all sixty-five pre- and post-paired surveys. The overall mean provider increase was 13.04 and significant ($t = -8.879, p < 0.001$). The cell size of specialty groups was too small for statistical analysis.

Table 6. Respondent Individual Specialty Mean Results and Combined Respondent Results.

<i>FERP Phase I</i>				<i>FERP Phase II</i>						
FERP PROVIDERS (n=118)	Total	PRE-Mean(118)	Range	FERP PROVIDERS (n=65)	Total	PRE-Mean(65)	Range	POST-Mean (65)	Range	Mean Diff (Increase)
General OBGYN	51	55.3	25-90	General OBGYN	37	57.03	25-90	69.86	30-90	12.83
FNP	15	64.12	40-80	FNP	5	63	45-80	78	45-85	15
Midwives	6	57.45	40-90	Midwives	6	56.66	50-90	69.16	55-90	12.5
Family Practice MD	4	58.5	20-85	Family Practice MD	4	57.5	20-80	70	30-85	12.5
MFM/Perinatal	29	51.3	35-95	MFM/Perinatal	9	52.7	45-95	66.66	40-95	19.9
Reproductive Endo	13	66.09	30-90	Reproductive Endo	4	67.5	35-85	86.25	40-85	18.75
Combined Overall Provider Mean Scores/Ranges (Phase I)	118	58.79	20-95	Combined Overall Provider Mean Scores/Ranges (Phase II)	65	57.54	20-95	70.58	30-95	13.04
Phase I- Participants responded to initial survey only (n=118)										
Phase II- Participants responded to initial and second survey (n=65)										

A post-survey provider score improvement of an average of 15% was noted in 89% of the respondents. However, 8% of the participating providers had a decrease in their post-survey scores, and unchanged post scores accounted for about 3% of the providers.

There was no significant correlation between time in practice and mean pre- or post-knowledge survey scores. Tabled data does, however, represent a trend toward higher scores in providers practicing in the time categories of six-to-ten years or greater (Table 7).

Table 7. TIP/Mean/Range Score

<i>FERP Phase I</i>				<i>FERP Phase II</i>						
Time in Practice(TIP) n=118	Total	PRE-Mean	Range	Time in Practice (TIP) n=65	Total	PRE-Mean(65)	Range	POST-Mean (65)	Range	Mean Diff (Increase)
0-5 yrs	11	50.1	35-90	0-5 yrs	7	47.85	35-90	60.71	40-90	12.86
6-10 yrs	34	64.32	20-85	6-10 yrs	23	57.39	25-85	71.3	30-85	13.91
11-15 yrs	22	55.5	25-85	11-15 yrs	11	61.36	25-90	70	30-90	8.64
16-20 yrs	22	58.2	30-95	16-20 yrs	11	59.54	35-95	73.63	40-95	14.09
> 20 yrs	29	59.62	35-90	> 20 yrs	13	61.15	35-90	75	40-90	13.85
Phase I- Participants responded to initial survey only										
Phase II- Participants responded to initial and second survey										

Discussion

Results of this study were positive, as scores indicated improved knowledge in the majority of the cases and the response rate was good for a mail survey. This initial assessment of pre-survey scores validated the experience of low referral rates for fetal echocardiography in the area.

The fetal echocardiography guidelines have been available to practitioners for more than a decade. The use of fetal echocardiography as a diagnostic tool was first described about forty years ago (Buzzard, 2004). The provider pre-dissemination scores on the knowledge survey ranged from 20% and 85% on the high end with a mean score of 58.6%. While the intervention had a significant increase in scores, the post-test mean was 70%. These results further substantiate the benefit of periodic updates being disseminated to busy providers.

Limitations

A number of limitations were identified in the process. A single southern California institution and area were the focus, thus generalizability may be limited. Provider bias with regard to the guidelines and what they believe or disbelieve with regard to referral indicators was not captured in this work. The specialties and provider types may indicate different training and expertise that may not include fetal echocardiography guidelines and should thus be included in subsequent surveys of similar nature.

Implications for nursing practice

The project indicates that fetal echocardiography guideline dissemination via a pre-prepared educational packet is a viable means of increasing provider knowledge. Given provider time constraints, self-study educational program with supplemental materials is feasible and a cost effective alternative to on-site training. Nurses in advanced practice roles should seek out opportunities to increase knowledge of guidelines relevant to their practice and be a catalyst for increasing the knowledge of other providers for which they work. Advanced practice nursing roles, such as implementing a quality improvement project like FERP in their own practice areas, are vital in increasing guideline knowledge not only for themselves, but also for others.

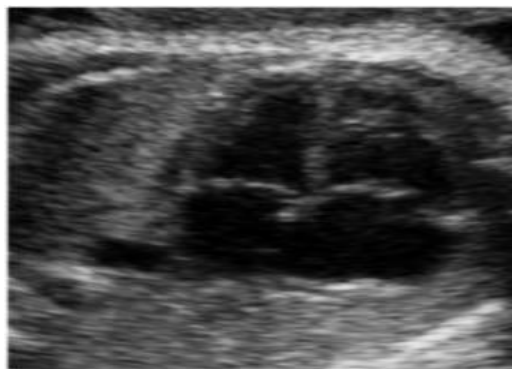
Conclusion

FERP focused on bridging the gap between evidenced-based practice guidelines and provider knowledge by utilizing an education intervention to disseminate well-established Fetal Echocardiogram Referral Guidelines. The project was comprised of a three-phase intervention approach to assess, promote, and evaluate obstetrical providers in the knowledge of Fetal Echocardiography Referral Guidelines. The overall project was guided by a Modified Stetler's Model of research Utilization to Facilitate Evidence-Based Practice. These results indicate a positive

relationship between FERP intervention and an increase in obstetrical provider knowledge as evidenced by a p value of < 0.01 on a paired-samples t-test (indicating a confidence interval of $>95\%$). The FERP project has shown that pre- and post-dissemination audits represent an effective method for increasing knowledge of fetal echocardiography guideline evidence of obstetrical providers in a fifty-mile referral area from a moderate-sized university medical center in southern California. This project showed that achieving increased knowledge in obstetrical providers was possible, and also showed that positive post-dissemination audit results were attainable and achieved through evidenced-based dissemination of the project and provider participation. Further study would be necessary to confirm the relationship after adjusting for all identified confounders.

Future Research and Considerations

The development, implementation and evaluation of project strategies to improve provider guideline knowledge are an important area of focus. Best practices associated with the dissemination of periodic guideline updates to practicing providers is hugely important, as these updates can elucidate and explain potentially applicable practice knowledge. This raises a crucial issue of keeping not only the guidelines up-to-date but ensuring that any changes are disseminated in a consistent and timely manner to all relevant parties.



Fetal Cardiac Imaging. Courtesy of Neda Mulla, MD. LLUMC Pediatric Cardiology

Competing Interests or Disclosures:

The authors declare there are no competing interests or disclosures to be made in association with this paper or the project it represents.

Appendix A. *Sentinel Events Cases.*

CASE I:

In 2009, an 11-month-old Trisomy 21 (Down's syndrome) was admitted to our Pediatric Intensive Care Unit for respiratory failure. Once an echocardiogram was obtained, a large Patent Ductus Arteriosus and Large Atrial Septal Defect were identified, and the significant pulmonary overflow was very evident on chest x-ray. Despite medication management and catheterization interventions in the lab, her degree of pulmonary hypertension remained significant. She spent 6 months in the hospital with multiple issues related to the pulmonary hypertension, nutrition, tracheal issues due to lengthy need for intubation and so forth.

This 11-month-old girl was diagnosed in utero via amniocentesis as having Trisomy 21. A fetal echocardiogram was ordered or performed nor was a newborn echocardiogram both of which are standards of care.

CASE II:

Another 2009 case of a 5-day-old male born at a local hospital with early and consistent prenatal care was rushed to our NICU and quickly diagnosed with Hypoplastic Left Heart Syndrome (HLHS). The infant male had low saturations since birth and was thought to have had a respiratory issue until the baby went into cardiovascular failure. Surgery eventually was done for palliation of this defect, but the length of time was increased as the baby needed to be stabilized for several days before any further interventions could be made.

This baby 7 years prior had a sibling die of HLHS post the Norwood procedure. The mother stated her OB assured her nothing was abnormal about this baby's heart in on ultrasound. The baby was never referred to a specialist for a fetal echocardiogram even though the guidelines clearly state this as an indicator.

CASE III:

In 2010 case a 4-week-old male with undiagnosed transposition of the great arteries (TGA) was brought by his parents to a local emergency room in respiratory and cardiac failure, saturations on pulse oximetry were at 16%, O₂ was applied and no change was seen. The patient was emergently transferred to our NICU; we were called as they were in transit and from clinical description by the referring hospital, and our team recognized what the likely defect would be. We were there when the infant arrived, saturations still in teens and severely cyanotic, intubated and nonresponsive. An echocardiogram was performed, and our suspicions were confirmed, it was Transposition of the Great Arteries. A Balloon Atrial Septostomy (BAS) was performed to allow for mixing as this baby only had a restrictive patent foramen ovale (PFO) and a closed Patent Ductus Arteriosus. Prostaglandin (PGE) was established in transit with no success at obtaining any ductal patency.

Despite the best efforts of this medical team and all collaborating parties, even an emergent attempt at palliation in the operating room he did not survive. This family, who had taken this beautiful baby boy home and loved him, now had to live with his loss. He had an older brother who had a ventricular septal defect (VSD) and under fetal echocardiogram guidelines that is an indicator for a fetal echocardiogram to be obtained.

Appendix B. Individual Evidence Summary Tables FERG's

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

Sarah Ann Keil Heinonen

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
1	American Society of Echocardiography (ASE). Rychik, J	2004	Guideline and Standards Statement	Fetal Echocardiogram Referral Guidelines I	<p>Maternal</p> <ul style="list-style-type: none"> Family History Metabolic Disorders Exposure to Teratogens Exposure to prostaglandin synthetase inhibitors Rubella Infection Autoimmune disease Familial inherited disorders In vitro fertilization <p>Fetal</p> <ul style="list-style-type: none"> Abnormal OB ultrasound Extracardiac abnormality Chromosomal abnormality Hydrops Increased Nuchal translucency thickness Multiple Gestations 		

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Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
2	American Heart Association (AHA)	2011	Guideline and Standards Statement	Fetal Echocardiogram Referral Guidelines	<ul style="list-style-type: none"> - If a first degree relative has been diagnosed with a congenital heart defect. First degree relative includes the mother or father of the baby as well as any siblings of the baby - If there is a known family history of disorders that are passed along from generation to generation such as Marfan's syndrome or tuberous sclerosis - If the unborn baby has been diagnosed with a genetic abnormality including disorders with abnormal number of chromosome; Down syndrome, for example - Abnormal amniocentesis - If the mother has taken medications that are known to cause congenital heart defects, Accutane, for example. - If the mother has specific health problems such as diabetes (the type that the mother had prior to pregnancy), phenylketonuria or autoimmune diseases such as systemic lupus erythematosus. - If the mother had specific infections during pregnancy such as rubella or CMV - If a heart abnormality is 		

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Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING Strength
							Quality
					suspected on routine ultrasound - If there are abnormalities outside of the heart of the fetus noted on routine prenatal ultrasound; examples include extra fluid around the lungs or the heart or an abnormality of another organ such as the kidneys or brain. - Abnormal fetal heart rate or rhythm. This can be an irregular heart beat or heart rate that is too fast or too slow.		

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING Strength
							Quality
3	International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) Lee, W	2006 / 2008	Guideline and Standards Statement	Fetal Echocardiogram Referral Guidelines	<p><i>Maternal Indications</i></p> Family history First-degree relative of POOR Pre-existing metabolic disease Diabetes Phenylketonuria Maternal infections Parvovirus B19 Rubella Coxsackie Cardiac toxin exposure Cardiac Diuretic Carbamazepine Lithium carbonate Valproic acid Maternal antibodies Anti-Ro (SSA) Anti-La (SSB)		
					<p><i>Fetal Indications</i></p> Suspected fetal heart anomaly Abnormal fetal karyotype Major extra cardiac anomaly Abnormal nuchal translucency "3.5 mm before 14 weeks" gestation Fetal cardiac rate or Persistent bradycardia rhythm disturbances Persistent tachycardia Persistent Irregular heart rhythm		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
4	UpToDate www.uptodate.com Copel, J	2011 (Updated)	Guideline and Standards Statement	Fetal Echocardiogram Referral Guidelines	<p>Familial Risk Factors Previous child w/CHD Paternal CHD Syndromes (VCF, Neurofibromatosis, Tumors/TB, etc.....)</p> <p>Maternal Risks Factors Maternal CHD Teratogen Exposure IDDM/PKU/SSA/SSB Exposure to Prostaglandin Inhibitor Rubella In vitro</p> <p>Fetal Risk Factors OB ultrasound suspicious Extracardiac Anomaly Aneuploidy Non-immune Hydrops Arrhythmia Abnormal Fetal situs Increased Nuchal Translucency Chromosomal abnormality Monochorionic twins, w/ or w/out twin-twin transfusion</p>		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
5	AETNA	2011	Clinical Policy Bulletin	Fetal Echocardiogram Referral Guidelines	<p>A mother with insulin dependent diabetes mellitus or systemic lupus erythematosus; or As a screening study in families with a first degree relative with a history of congenital heart disease; or Following an abnormal or incomplete cardiac evaluation on an anatomic scan, 4-chamber study. (Note: When the 4-chambered view is adequate and there are no other indications of a cardiac abnormality, a fetal echocardiogram is not considered medically necessary); or For ductus arteriosus dependent lesions and/or with other known complex congenital heart disease; or For pregnancies conceived by in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI); or In cases of single umbilical artery; or In cases of suspected or known fetal chromosomal abnormalities; or In suspected or documented</p>		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
					fetal arrhythmia; to define the rhythm and its significance, to identify structural heart disease and cardiac function; or Members with seizure disorders, even if they are not presently taking anti-seizure medication; or Non-immune fetal hydrops; or When members' fetuses have been exposed to drugs known to increase the risk of cardiac abnormalities including but not limited to: Anti-seizure medications; or Excessive alcohol intake; or Lithium; or Paroxetine (Paxil); or When other structural abnormalities are found on ultrasound. Aetna considers repeat studies of fetal echocardiograms medically necessary when the initial screening study indicates any of the following: A ductus arteriosus dependent lesion; or Structural heart disease with a suggestion of hemodynamic compromise; or Tachycardia other than sinus tachycardia or heart block.		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	Strength
							Quality
6	American Institute of Ultrasound in Medicine	2010	AIUM Practice Guideline for the Performance of Fetal Echocardiography	Fetal Echocardiogram Referral Guidelines	<u>Maternal Indications</u> <ul style="list-style-type: none"> • Autoimmune antibodies, anti-Ro (SSA)/anti-La (SSB); • Familial inherited disorders (eg, Marfan syndrome); • First-degree relative with congenital heart disease; • In vitro fertilization; • Metabolic disease (eg, diabetes mellitus and phenylketonuria); and • Teratogen exposure (eg, retinoids and lithium). <u>Fetal Indications</u> <ul style="list-style-type: none"> • Abnormal cardiac screening examination; • Abnormal heart rate or rhythm; • Fetal chromosomal anomaly; • Extracardiac anomaly; • Hydrops; • Increased nuchal translucency; • Monochorionic twins; and • Unexplained severe polyhydramnios. 		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING Strength
							Quality
7	Kaiser – TPMG Regional Pediatric Cardiology and Perinatology Groups. Fetal Cardiology Workgroup 7/29/10	2010	Recommendations for Cardiac Screening and Diagnosis in the Fetus	Fetal Cardiology Evaluation, Referral and Echocardiogram Guidelines	<p>Indications for a Fetal Cardiology Evaluation (these are expected to be referred):</p> <ol style="list-style-type: none"> 1. Abnormal cardiac findings on any fetal ultrasound. 2. Fetal tachycardia persistently over 180 bpm, bradycardia persistently below 100 bpm, or any hemodynamically significant fetal dysrhythmia on screening ultrasound. 3. Any pregnancy in which termination is considered due to fetal cardiac abnormalities. <p>Indications for Formal Fetal Echocardiogram (referral strongly recommended):</p> <ol style="list-style-type: none"> 1. Major fetal abnormalities highly associated with cardiac pathology such as: <ol style="list-style-type: none"> a. Chromosomal Abnormalities highly associated with CHD (i.e. Down Syndrome) b. Trisomy 13 and 18 if pregnancies are not terminated. c. Heterotaxy Syndromes (Polysplenia/Asplenia) d. VATER or VACTERL Associations. 		

**Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines**

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING Strength
							Quality
					<ol style="list-style-type: none"> 2. Maternal systemic lupus erythematosus (SLE) with evidence of bradycardia or prolongation of the A-V interval. 3. Pre-gestational Diabetics with suboptimal fetal cardiac screening ultrasound. 4. Fetuses requiring fetal cardiac screening ultrasound (see below) where all components of a fetal cardiac screening ultrasound cannot be obtained. <p>Indications for Fetal Cardiac Screening Ultrasound:</p> <ol style="list-style-type: none"> 1. Family history of congenital heart disease (excluding patent ductus arteriosus) in mother, father, or siblings. These patients are often known to pediatric cardiologists that are following the first degree relative and may be directly referred by the cardiologist. 2. Pre-gestational Diabetics. 3. Elevated fetal nuchal translucency measurements > 3.0 mm between 10-3/7 and 13-6/7 weeks should be evaluated with a fetal 		

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
					cardiac screening ultrasound. Recommendations for additional testing such as a formal fetal echocardiogram, will be determined by Perinatology.		Quality

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
8	American College of Cardiology / American Heart Association	2003	ACC/AHA Practice Guidelines Guideline Update for the Clinical Application of Echocardiography	Fetal Echocardiography Pages 67-68	<p>Class I</p> <ol style="list-style-type: none"> 1. Abnormal-appearing heart on general fetal ultrasound examination. 2. Fetal tachycardia, bradycardia, or persistent irregular rhythm on clinical or screening ultrasound examination. 3. Maternal/family risk factors for cardiovascular disease, such as a parent, sibling, or first-degree relative with congenital heart disease. 4. Maternal diabetes. 5. Maternal systemic lupus erythematosus. 6. Teratogen exposure during a vulnerable period. 7. Other fetal system abnormalities (including chromosomal). 8. Performance of transplacental therapy or presence of a history of significant but intermittent arrhythmia. Re-evaluation examinations are required in these conditions. <p>Class IIa</p>		

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
					<p>Fetal distress or dysfunction of unclear etiology.</p> <p>Class IIb</p> <ol style="list-style-type: none"> 1. Previous history of multiple fetal losses. 2. Multiple gestation. <p>Class III</p> <ol style="list-style-type: none"> 1. Low-risk pregnancies with normal anatomic findings on ultrasound examination. 2. Occasional premature contractions without sustained tachycardia or signs of dysfunction or distress. 3. Presence of a noncardiovascular system abnormality when evaluation of the cardiovascular system will not alter either management decisions or fetal outcome. 		

Individual Evidence Summary Table
Fetal Echocardiogram Referral Guidelines

#	1 st Author	Year	Level of research (or non-research) evidence	Sample Composition & Size	Results/ Recommendations	Limitations	RATING
							Strength
							Quality
9	Blue Cross Blue Shield	1995 Updated 2003	Medical Policy OB/GYN Reproduction	Fetal Echocardiography	<p>Fetal Risk Factors:</p> <ul style="list-style-type: none"> • extracardiac abnormality; • chromosomal abnormality; • fetal cardiac arrhythmia; • non-immune hydrops; • question of cardiac anomaly on prior sonogram; • intrauterine growth retardation. <p>Maternal Risk Factors:</p> <ul style="list-style-type: none"> • family history of CHD (parent or sibling); • teratogenic exposure (e.g., alcohol, amphetamines, anticonvulsives, lithium); • maternal disorders (e.g., diabetes mellitus, collagen vascular disease, phenylketonuria); • maternal infection (e.g., rubella); • familial syndromes. 		

Appendix C. Review of Literature Inclusion Studies

Review of Literature Articles and Barriers to Guideline Use

STUDY	Lack of Support	Time Constraints	Provider Beliefs	Lack of Knowledge	Presentation
<u>Fracke, Anneke L; 2008</u>	x	x		x	x
Van den Berg, MJ; 2009		x			
Baiardini, I; 2009	x		x	x	x
Graham, ID; 2004	x		x		x
Forsner, T; 2010	x		x		x
Grimshaw, JM; 2002	x	x	x	x	
Smith, WR; 2000	x		x	x	x
Solberg, LI; 2000	x			x	
<u>Lugtenberg, M; 2009</u>			x	x	
<u>Sammer, CE; 2008</u>	x				x
<u>Carlsen, B; 2007</u>	x		x		x

Key.

<u>Lack of Support</u>	<u>Time Constraints</u>	<u>Provider beliefs</u>	<u>Lack of knowledge</u>	<u>Presentation</u>
<u>Team/Patient Attitudes</u>	Ease of Use	<u>Past Experiences</u>	Staff/Provider/Team	Usefulness
Organization	Ease of Updates	Resistance to change	<u>Info overload</u>	Ease
Leadership	Provider time	Medical legal issues	Poor appraisal skills	Feasibility
Political Context	Workload	Concern @ practice control	Poor training	Electric format
System inefficiencies	Work of guideline	Belief @ EBP	Lack of Education	Paper format
Environment		Suspicious motives		Placement
Social/cultural context		Lack of agreement		<u>Guideline chara</u>
		Reliability		Ambiguity

Appendix C. (continued)

Review of Literature Articles and Interventions for Guideline Use

STUDY	Education Approach	Peer Approach	Presentation/Ease of Use Approach	Systems Approach
<u>Jamtvedt, G; 2006</u>				x
<u>Schectman, JM; 2003</u>	x			x
<u>Fletcher, RH; 2008</u>	x		X	
<u>Francke, Anneke; 2008</u>	x	x		
<u>Caminiti, Caterina; 2005</u>		x		x
<u>Grimshaw, JM; 2004</u>	x			x
<u>Hakkennes, S; 2008</u>	x	x		
<u>Stone, TT; 2005</u>	X	x	X	
<u>Prior, M; 2008</u>	x	X		x
<u>Zwarenstein, M; 2009</u>		X		
<u>Matchar, DB; 2005</u>	x	x		
<u>Graham, ID; 2004</u>		X		x
<u>Forsetlund, L; 2009</u>	x			x
<u>Grimshaw, J; 2006</u>	x			x
<u>Farmer AP; 2008</u>	x			
<u>Rebbeck, T; 2006</u>	X	X		
<u>Chaillet, N; 2006</u>	x	X		x
<u>Freemantle, N; 2007</u>	x			x
<u>O'Brien, MA; 2007</u>	x			x
<u>Akbari, A; 2008</u>	x	x	x	x

Appendix C. (continued)

<u>Medves, J</u> ; 2009	x	x		x
Wright, J; 2003				x
<u>Grimshaw, JM</u> ; 2001	x			
<u>O'Brien, MA</u> ; 2007				x
<u>Jousimaa, J</u> ; 2002			x	
<u>Gulmezoglu, AM</u> ; 2004	x	x		
Doherty, S ; 2006	x	x		x
Smith, WR.; 2000	x			
<u>Ockene, JK</u> ; 2000	x	x		
Solberg, LI.; 2000		x		x
<u>Eccles, MP</u> ; 2004			x	x
Beck, SL.; 2002	x			x
<u>Sammer, CE</u> ; 2008	x			

Key.

<u>Education Approach</u>	<u>Peer Approach</u>	<u>Presentation/Ease of Approach</u>	<u>Systems Approach</u>
Ed outreach programs/interventions	Peer reviewed journals	Printed Ed materials	<u>Computerized format</u>
Printed <u>ed</u> materials	Video conferencing	Front chart placement	Medical legal issues
Clinical education	Audio conferencing	Flow charts/algorithms	Reminder systems
Discussions w/ medical advisor	<u>Interprofessional meetings</u>	Preprinted orders	Audit and feedback
Theory driven	Local consensus process	Computerized formatting	Organization
		Structured referral sheets	

Appendix C. (continued)

Recommended approaches to guideline implementation

STUDY	Single Strategic Approach	Multi-faceted (pronged) strategic approach	Identify Barriers and Individualize
Jamtvedt, G; 2006	x		
Schechtman, JM; 2003		x	
Fletcher, RH; 2008	x		
Francke, Anneke; 2008		x	
Caminiti, Caterina; 2005		x	x
Van den Berg, MJ; 2009	N/A	N/A	N/A
Grimshaw, JM; 2004			x
Hakkennes, S; 2008			x
Stone, TT; 2005			x
Prior, M; 2008		x	
Zwarenstein, M; 2009	x		
Baiardini, I; 2009			x
Matchar, DB; 2005			x
Graham, ID; 2004			x
Forsetlund, L; 2009		x	
Forsner, T; 2010			x
Grimshaw, J; 2006			x
Farmer AP; 2008	x		
Rebbeck, T; 2006	X		

Appendix C. (continued)

<u>Chaillet, N</u> ; 2006	x	x	x
Freemantle, N; 2007		x	
O'Brien, MA; 2007	x	x	
<u>Akbari, A</u> ; 2008		x	
<u>Medves, J</u> ; 2009		x	
Wright, J; 2003		x	
<u>Grimshaw, JM</u> ; 2001		x	
<u>O'Brien, MA</u> ; 2007	X	x	
<u>Jousimaa, J</u> ; 2002		X	x
<u>Grimshaw, JM</u> ; 2002			x
<u>Gulmezoglu, AM</u> ; 2004		x	x
Doherty, S; 2006		x	
Smith, WR.; 2000		x	
<u>Ockene, JK</u> ; 2000		x	
Solberg, LI.; 2000		x	
<u>Eccles, MP</u> ; 2004	x		
Beck, SL.; 2002		X	x
<u>Lugtenberg, M</u> ; 2009			x
<u>Sammer, CE</u> ; 2008		x	
<u>Carlsen, B</u> ; 2007			x

Appendix D. *FERG'S*

Fetal Echocardiography Referral Guideline's

<u>Maternal Indicators</u>	<u>Fetal Indicators</u>	<u>Familial Indicators</u>	<u>Follow up Echocardiograms</u>
Family history	Abnormal amniocentesis	Relative with congenital heart disease	Ductus arteriosus dependant Lesions
Metabolic disorders (IDDM/PKU)	Abnormal fetal heart rhythm	Syndromes (VCF/Noonan's/Turners/TS/etc.....)	CHD with suggestion of hemodynamic compromise
Exposure to Teratogens	Abnormal OB ultrasound	Familial inherited disorders	Fetal hydrops
Exposure to prostaglandin synthetase inhibitors	Extra cardiac abnormality	(ICIS) Intracytoplasmic Sperm Injection	
Viral infections during pregnancy (Rubella/Parvo/Coxsackie)	Chromosomal abnormality		
Autoimmune disease (SSA / SSB / SLE)	Fetal hydrops		
In vitro fertilization	Polyhydraminos		
Maternal CHD	Intrauterine Growth Retardation (IUGR)		
Maternal seizure disorder	Fetal Distress		
	Multiple gestations		
	Increased nuchal translucency thickness		
	Abnormal ductal venosus waveform		
	Aneuploidy		
	Abnormal fetal situs		
	Monochorionic twins, with or without twin-twin transfusion		
	1 or 2 vessel umbilical cord		

Appendix E.

Survey writing resources utilized for creating the FERP questionnaire

FERP Knowledge Survey References
Division of Instructional Innovation and Assessment, The University of Texas at Austin. "Writing Survey Questions." Instructional Assessment Resources. 2007. texas.edu/academic/diia/assessment/iar/teaching/plan/method/survey/writing.php
Division of Instructional Innovation and Assessment, The University of Texas at Austin. "Organizing and Formatting Surveys." Instructional Assessment Resources. 2007. http://www.utexas.edu/academic/diia/assessment/iar/teaching/plan/method/survey/format.php
Division of Instructional Innovation and Assessment. The University of Texas at Austin. "Survey Planning." Instructional Assessment Resources. 2007. http://www.utexas.edu/academic/diia/assessment/iar/research/plan/method/survey.php
Driscoll, DL. (2006). "Creating Good Interview and Survey Questions." Retrieved September 14, 2007, from The Owl at Purdue: http://owl.english.purdue.edu/owl/resource/559/06/
Niederhauser, V. P., & Mattheus, D. (2010). The Anatomy of Survey Questions. <i>Journal of Pediatric healthcare</i> , 24, 351-354.
SMART SURVEY DESIGN. (2008). Survey Monkey. s3.amazonaws.com/SurveyMonkeyFiles/SmartSurvey.pdf
Waddington, H. (2000). Types of survey questions. In B. Hoffman (Ed.), <i>Encyclopedia of Educational Technology</i> (pp. X-Y). Retrieved February 28, 2007, from: http://coe.sdsu.edu/eet/Articles/surveyquest/start.htm

Appendix F. FERP Phase I Documents

FERP Phase I Letter

Dear Provider:

My name is Sarah Ann Keil Heinonen and I am a Doctoral student at Johns Hopkins University as well as a Pediatric Cardiology Nurse Practitioner at Loma Linda Medical Center and Children's Hospital.

I am currently working on my Capstone Doctoral Project and my area of focus is Fetal Cardiology. Enclosed is a fetal echocardiogram referral guideline and practice knowledge questionnaire.

I would really appreciate it if you would take the time to fill out the questionnaire and return it in the envelope provided. Please only return the survey portion of the materials in the provided envelope. Your participation is the only way I can learn more about area provider's baseline knowledge on indicators for fetal echocardiogram referrals as well as practices in hopes of improving patient's outcomes.

You were selected because you are an obstetrical provider in the referral area for Loma Linda Medical Center and Children's Hospital. This does not mean you refer to Loma Linda University Medical Center/Children's Hospital just that you are in the referral region.

Your participation is, of course, voluntary. The responses you provide will be combined with the information we get from other participants. Your individual answers will never be disclosed. All information about you will be strictly Confidential.

If I do not receive a response within the next 2 weeks, I will attempt to contact you by telephone to complete the survey. If at any time you decide that you would prefer not to participate, simply return the blank survey in the stamped envelope provided. I will make no further attempts to contact you.

I hope you will take this opportunity to tell me about your referral practices in hopes of improving Fetal Cardiac Medicine and Outcomes. I know as you have dedicated your life to your chosen career you understand the importance of this topic.

If you would like to know more about the survey, please contact Sarah Ann Keil Heinonen at -----

Sincerely,

Sarah Ann Keil Heinonen, APRN, MSN, C-PNP (DNP Student)

Fact Sheet

Fetal Echocardiogram Referral Survey

Who is doing the study?

Myself as a Doctoral Student at Johns Hopkins University in conjunction with the Pediatric Cardiology Division at Loma Linda University Medical Center under the mentorship of Dr. Neda Mulla.

What is Source of Funding?

Currently Myself. This study is not currently funded, and I have no disclosures to make. Grants have been applied for and if funding is obtained that disclosure will be made to all participants.

What is the purpose?

To gain knowledge on referral knowledge and practices of area obstetrical providers for Fetal Echocardiogram and for the benefit of my Capstone Doctoral Project and Dissertation.

How was I selected?

You are noted to be an obstetrical provider in the referral area for Loma Linda University Medical Center and Children's Hospital.

What kinds of questions will be asked?

Questions pertaining only to fetal echocardiogram referral guidelines and practices.

Are my answers confidential?

Absolutely. Your answers will never be used in any way that could be linked to you or your practice. They will be combined with answers from other surveys to create a statistical report and will be tracked only by a reference number.

Do I have to answer?

No. Your help is completely voluntary. Your decision to Participate.

What is the incentive?

Personal and professional support of academic research, knowledge and improved outcomes. You will not be paid for your participation.

FERP Phase I (and III) Knowledge Survey Example Questions

You are completing this survey or questionnaire will serve as your consent to be in this research study.

1. Which of the following items is not an indicator for a referral for a Fetal Echocardiography?

- a) Maternal seizure disorder
- b) Family history of CHD
- c) Mumps
- d) Metabolic disorders
- e) None of the above

2. All of the following are true except:

- a) An abnormal amniocentesis is an indicator for a fetal echocardiogram.
- b) A follow up fetal echocardiogram is indicated when a ductal dependent lesion has been diagnosed.
- c) A pregnant woman with a seizure disorder may be at higher risk and does indicate a fetal echocardiogram.
- d) A prior premature birth is an indication for a fetal echocardiography.

3. Which of the following items is an indicator for a referral for a fetal echocardiogram?

- a) In vitro fertilization
- b) Fetal distress
- c) 2 vessel umbilical cord
- d) Abnormal OB ultrasound
- e) a, b, and c only
- f) All of the above
- g) a, c, and d only

4. Which of the following abnormal finding is not an indicator for a fetal echocardiogram referral?

- a) Abnormal amniocentesis
- b) Abnormal ductal venous waveform
- c) Abnormal maternal swelling
- d) Abnormal fetal heart rhythm
- e) None of the above

5. What is the advantage of an early discovery of a fetal heart defect?

- a) Early detection and monitoring will prepare the necessary resources for early intervention
- b) Early detection allows for improved parental decision-making and preparation.
- c) Early detection provides more options for families.
- d) Early detection and preparation improves outcomes
- e) All of the above

REFERRAL PRACTICES

1. How many patients do you refer annually for a fetal echocardiogram?

- a. None
- b. 1-5
- c. 6-10
- d. >10

2. Which type of provider do you refer your patients to for fetal echocardiography?

- a. High Risk Obstetrician
- b. Diagnostic Center
- c. Pediatric Cardiologist
- d. Other (Specify _____)

3. Which Institution or facility do you routinely refer to?

4. What is your primary reason for choosing to refer to that provider or institution?

- a. Affiliation with provider/institution
- b. Insurance demands
- c. Reputation
- d. Personal preference
- e. Other specify _____)

5. How long have you been in practice?

- a. 0-5 years
- b. 6-10 years
- c. 11-15 years
- d. 15-20 years
- e. > 20 years

FERP Phase I Reminder Cards



Appendix G. FERP Phase II Documents

FERP Phase II Letter

Dear Provider:

My name is **Sarah Ann Keil Heinonen** and I am a Doctoral student at **Johns Hopkins University**. I recently contacted you with regard to my **Doctoral Capstone Project** focusing on **Fetal Cardiology** and in doing so I had requested your participation in completing and returning a **knowledge survey about fetal echocardiogram referral indicators**.

Due to your gracious participation, I have **enclosed fetal echocardiogram referral guidelines, evidence to support those guidelines** as well as a **referral form specific for fetal echocardiography**. The hope with this is to improve ease of guideline implementation into your practice if you do not currently have a system in place for this process.

Your participation continues to be voluntary of course and any past and/or future responses you provide will be combined with the information we get from the other participants. Your individual answers will never be disclosed and all information about you will be kept strictly **Confidential**.

I would really appreciate it if you would take the time to review the information provided in these **Fetal Echocardiogram Referral Packets**, as my intention is to follow these up with a post survey.

As I mentioned previously and continue to firmly believe that as you have dedicated your life to your chosen career you understand the importance of this particular topic.

If you would like any additional information, please contact (me) **Sarah Ann Keil Heinonen at -----**

Sincerely,
Sarah Ann Keil Heinonen, APRN, MSN, C-PNP
Doctoral Candidate

Johns Hopkins eIRB Study # NA_00046110/ PI Sarah Shaefer JHUSON

Loma Linda University Children's Hospital IRB # 5110012 PI Neda Mulla, MD LLUCH

FERP Phase II FERG Abstract

Abstract

Background: Clinical guidelines aim to improve the safety and quality of patient care by providing clinicians with formal recommendations based on evidence of best practice. Such guidelines currently do exist for obstetrical providers on referral indicators for fetal echocardiograms. Congenital heart defects (CHD) are the number one birth defect and the leading cause of infant and newborn death in the US, with approximately 40,000 babies born each year, this is about 1 out of every 115 to 125 babies born have some form of CHD (AHA 2010), and yet, pregnant women are not routinely tested, and newborns are not routinely screened. Three out of five women who have given birth to a child with a congenital heart defect (CHD) were never tested for the defect during their pregnancy (Cameron, L. 2010).

Objective: The purpose of this guideline review is to outline and describe fetal echocardiography referral guideline indicators in order to aid in the utilization, implementation and consistency of practice associated with fetal echocardiography referrals.

Problem statement: The association with low fetal echocardiogram referral rates, high rates of postnatally diagnosed CHD* with prenatal indicators for referral identified and the increased risk of morbidity and mortality in this group.

Search Strategy: A comprehensive search of 6 electronic databases (e.g. MEDLINE/PUBMED, EMBASE) including a specialized database (e.g. Cochrane Library), as well as a manual search of reference lists from both the primary and review articles were utilized to identify literature pertaining to fetal echocardiogram referral guidelines.

Selection Criteria: Studies for inclusion were based on topic, keywords*, English language, Human Studies, abstract and full text availability. Studies were reviewed from 2000 to 2010, with all fetal echocardiogram referral indicators noted and reviewed. Ultimately, organizations pertaining to sonography and obstetrical care as well as large healthcare insurance providers that have published their well-established fetal echocardiogram guidelines were utilized for this review.

Data collection and analysis: I reviewed and tabulated all reported and published fetal echocardiography referral guideline indicators. Consequently, all results are summarized and presented in a narrative and table format.

Results: Nine published guideline sources were identified and met the inclusion criteria; three main indicator categories were identified with one subsequent follow-up indicator category. Thirty-two individual indicators were identified and noted throughout the clinical practice guidelines published. All reviewed documents supported the use of fetal echocardiography referral guidelines in obstetrical provider practice to improve overall quality of patient and family care.

Conclusions: Technological advances as with fetal echocardiography provide many opportunities to improve the outcomes of patient care, but technology alone cannot obtain these goals. Clinical practice guidelines were created to ensure best evidence could be translated into best practice. Guidelines alone are not enough; provider knowledge, implementation and consistent utilization of these guidelines in their own practice are paramount in the early detection of congenital heart disease. It is this early detection that allows for the improvement of outcomes and the overall

decrease of morbidity and mortality associated with late postnatal diagnosis of congenital heart disease.

****Keywords:** Fetal Echocardiography Practice Guidelines, Sonography, Fetal Cardiology (CHD* - Congenital Heart Disease/Defects).

References

1. Aetna. (2010). Clinical Policy Bulletin: Fetal Echocardiograms. Copyright AETNA Inc. 2010. Number: 0106. Policy.
2. American College of Cardiology / American Heart Association. (2003). ACC/AHA Practice Guidelines. Guideline Update for the Clinical Application of Echocardiography. Fetal Echocardiography. Pages 67-68.
3. American College of Gynecology (ACOG). (2008). ACOG Practice Bulletin. Ultrasonography in pregnancy. Journal of Obstetrical Gynecology 2008; 112:951.
4. American Heart Association. (2008). Fetal Echocardiography. Our guide to specialized testing for expectant parents. www.americanheart.org.
5. American Institute of Ultrasound in Medicine. (2010). AIUM Practice Guideline for the Performance of Fetal Echocardiography. Fetal Echocardiogram Referral Guidelines
6. Kaiser – TPMG Regional Pediatric Cardiology and Perinatology Groups. (2010). Recommendations for Cardiac Screening and Diagnosis in the Fetus Fetal Cardiology Evaluation, Referral and Echocardiogram Guidelines. Fetal Cardiology Workgroup 7/29/10.
7. Blue Cross Blue Shield. (1995). Medical Policy. OBGYN Reproduction. Fetal Echocardiography. Updated 2003.
8. Cameron, L. (2010). Most Pregnant Women Never Tested for the Most Common Birth Defect. Little Hearts Organization. (2010). Connecticut. USA. http://www.healthnewsdigest.com/news/Women_s_Health_260/Most_Pregnant_Women_Never_Testted_for_the_Most_Common_Birth_Defect.shtml
9. Lee, W., Allan, J., Carvalho, JS., Chaoui, R., Copel, G., Devore, G., Hecher, K., Munoz, H., Nelson, T., Paladini, D., and Yagel, S. (2008). ISUOG consensus statement: what constitutes a fetal echocardiogram? International Society of Ultrasound in Obstetrics and Gynecology. Copyright 2008. John Wiley & Sons Ltd.
10. Rychik, J., Ayres, N., Cuneo, B., Gotteiner, N., Hornberger, L., Spevak, P., and Van Der Veld, M. (2004). American Society of Echocardiography Guidelines and Standards for Performance of the Fetal Echocardiogram. American Society of Echocardiography Report. Journal of American Society of Echocardiography 2004; 17:803-10. Copyright 2004 ASE.
11. Sharland G. (2009). Fetal Cardiac Screening; why bother? Archives of Disease in Childhood. Published online 17 August 2009; doi: 1136/adc.2008.15122.
12. Statistics on Congenital Heart defects. American Heart Association. 2008.

<http://www.americanheart.org/.../heart/1198008486846FS20CCD08.doc>

Maternal Indicators:

- o Family history
- o Metabolic disorders (IDDM/PKU)
- o Exposure to Teratogens
- o Exposure to prostaglandin synthetase inhibitors (
- o Viral infections during pregnancy (Rubella/Parvo/Coxsackie)
- o Autoimmune disease (SSA / SSB / SLE)
- o In vitro fertilization
- o Maternal CHD
- o Maternal seizure disorder

Familial Indicators:

- o Relative with congenital heart disease
- o Syndromes (VCF/Noonan's/Turners/TS/etc.....)
- o Familial inherited disorders
- o (ICIS) Intracytoplasmic Sperm Injection

Fetal Indicators:

- o Abnormal amniocentesis
- o Abnormal fetal heart rhythm
- o Abnormal OB ultrasound
- o Extra cardiac abnormality
- o Chromosomal abnormality
- o Fetal hydrops
- o Polyhydramnios
- o Intrauterine Growth Retardation (IUGR)
- o Fetal Distress
- o Multiple gestations
- o Increased nuchal translucency thickness
- o Abnormal ductal venous waveform
- o Aneuploidy
- o Abnormal fetal situs
- o Monochorionic twins, with or without twin-twin transfusion
- o 1 or 2 vessel umbilical cord

Follow-up Echocardiograms:

- o Ductus arteriosus dependent Lesions
- o CHD with suggestion of hemodynamic compromise
- o Fetal hydrops

GUIDELINE REFERENCES

1. Aetna. (2010). Clinical Policy Bulletin: Fetal Echocardiograms. Copyright AETNA Inc. 2010. Number: 0106. Policy.
2. American College of Gynecology (ACOG). (2008). ACOG Practice Bulletin. Ultrasonography in pregnancy. Journal of Obstetrical Gynecology 2008; 112:951.
3. American Heart Association. (2008). Fetal Echocardiography. Our guide to specialized testing for expectant parents. www.americanheart.org.
4. Lee, W., Allan, J., Carvalho, JS., Chaoui, R., Copel, G., Devore, G., Hecher, K., Munoz, H., Nelson, T., Paladini, D., and Yagel, S. (2008). ISUOG consensus statement: what constitutes a fetal echocardiogram? International Society of Ultrasound in Obstetrics and Gynecology. Copyright 2008. John Wiley & Sons Ltd.
5. Rychik, J., Ayres, N., Cuneo, B., Gotteiner, N., Hornberger, L., Spevak, P., and Van Der Veld, M. (2004). American Society of Echocardiography Guidelines and Standards for Performance of the Fetal Echocardiogram. American Society of Echocardiography Report. Journal of American Society of Echocardiography 2004; 17:803-10. Copyright 2004 ASE.
6. American Institute of Ultrasound in Medicine. (2010). AIUM Practice Guideline for the Performance of Fetal Echocardiography. Fetal Echocardiogram Referral Guidelines
7. Kaiser – TPMG Regional Pediatric Cardiology and Perinatology Groups. (2010). Recommendations for Cardiac Screening and Diagnosis in the Fetus Fetal Cardiology Evaluation, Referral and Echocardiogram Guidelines. Fetal Cardiology Workgroup 7/29/10.
8. American College of Cardiology / American Heart Association. (2003). ACC/AHA Practice Guidelines. Guideline Update for the Clinical Application of Echocardiography. Fetal Echocardiography. Pages 67-68.

Fetal Echocardiogram Referral Guidelines

(Adapted Guidelines by Sarah Ann Keil Heinonen, APRN, MSN-Pediatric Cardiology NP and Fetal Hearts Program Coordinator)

Maternal Indicators:

- ✓ Family history
- ✓ Metabolic disorders (IDDM/PKU)
- ✓ Exposure to Teratogens
- ✓ Exposure to prostaglandin synthetase inhibitors (
- ✓ Viral infections during pregnancy (Rubella/Parvo/Coxsackie)
- ✓ Autoimmune disease (SSA / SSB / SLE)
- ✓ In vitro fertilization
- ✓ Maternal CHD
- ✓ Maternal seizure disorder

Familial Indicators:

- ✓ Relative with congenital heart disease
- ✓ Syndromes (VCF/Noonan's/Turners/TS/etc.....)
- ✓ Familial inherited disorders
- ✓ (ICIS) Intracytoplasmic Sperm Injection

Fetal Indicators:

- ✓ Abnormal amniocentesis
- ✓ Abnormal fetal heart rhythm
- ✓ Abnormal OB ultrasound
- ✓ Extracardiac abnormality
- ✓ Chromosomal abnormality
- ✓ Fetal hydrops
- ✓ Polyhydramnios
- ✓ Intrauterine Growth Retardation (IUGR)
- ✓ Fetal Distress
- ✓ Multiple gestations
- ✓ Increased nuchal translucency thickness
- ✓ Abnormal ductal venous waveform
- ✓ Aneuploidy
- ✓ Abnormal fetal situs
- ✓ Monochorionic twins, with or without twin-twin transfusion
- ✓ 1 or 2 vessel umbilical cord

Follow-up Echocardiograms:

- ✓ Ductus arteriosus dependant Lesions
- ✓ CHD with suggestion of hemodynamic compromise
- ✓ Fetal hydrops

References

1. Aetna (2009). Clinical Policy Bulletin: Fetal Echocardiograms.
 - a. www.aetna.com/cpb/medical/data/100_199/0106.html
2. American College of Gynecology Practice Bulletin (2008). Ultrasonography in pregnancy. *Obstetrical Gynecology* 2008; 112:951. *American College of Gynecology (ACOG). Up-To-Date. www.uptodate.com 2010.*
3. American Heart Association (AHA) (2008). Fetal Echocardiography. www.americanheart.org.
4. Lee, W., Allan, L., Carvalho, J.S., Chaoui, R., Copel, J., Devore, G., Hecher, K., Munoz, H., Nelson, T., Paladini, D., Yagel, S., (2008). International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) consensus statement: what constitutes a fetal echocardiogram? *Ultrasound Obstet Gynecol*, 32: 239-242.
5. Rychik, J., Ayres, N., Cuneo, B., Gotteiner, N., Hornberger, L., Spevak, P., and Van Der Veld, M. (2004). American Society of Echocardiogram Guidelines and Standards for Performance of fetal echocardiogram. American Society of Echocardiography Report. *Journal of American Society of Echocardiogram* ; 17:803-10

FERP Phase II Guideline Tables

GUIDELINE SOURCE	Family History	Metabolic Disorders (IDDM/PKU)	Teratogens Exposure	Exposure to PGE synthetase inhibitors	Viral infections during pregnancy (Rubella / Parvo / Cocksaxie)	Autoimmune diseases (SSA / SSB / SLE)	Familial inherited disorders	IVF	Previous child w/CHD	Syndromes (e.g. VCF, Noonan's, Turner's)	Abnormal Amnio / Chromes	Abnormal Fetal Heart Rhythm
American Society of Echocardiography (ASE)	X	X	X		X	X	X	X	X	X	X	
American Heart Association (AHA)	X	X	X		X	X	X		X		X	X
International Society of Ultrasound Obstetrics and Gynecology (ISUOG)	X	X	X		X	X			X		X	X
AETNA Insurance	X	X	X	X		X		X	X		X	X
American Institute of Ultrasound Medicine (AIUM)	X	X	X			X	X	X	X		X	X
KAISER Insurance	X	X				X			X	X	X	X
American College of Cardiology (ACC)	X	X	X			X			X		X	X
Blue Cross Blue Shield Insurance	X	X	X		X	X	X		X	X	X	X
Up-To-Date	X	X	X	X	X	X			X	X	X	

GUIDELINE SOURCE	ICIS Intracytoplasmic Sperm Injection	Abnormal OB ultrasound / Extracardiac abnormalities	Fetal Hydrops / Polyhydraminos	Multiple Gestations	Increased nuchal translucency thickness	Abnormal Fetal Situs	Monochromic Twins (with or without twin-twin transfusion syndrome)	IUGR	2 Vessel umbilical Cord	Maternal seizure disorder/ Anti seizure med exposure
American Society of Echocardiography (ASE)		X	X	X	X					X
American Heart Association (AHA)		X	X							X
International Society of Ultrasound Obstetrics and Gynecology (ISUOG)		X			X					X
AETNA Insurance	X	X	X						X	X
American Institute of Ultrasound Medicine (AIUM)		X	X		X		X			X
KAISER Insurance		X			X					
American College of Cardiology (ACC)		X		X						
Blue Cross Blue Shield Insurance		X	X					X		
Up-To-Date		X	X		X	X	X			

Appendix H. FERP Phase III Documents

FERP Phase III Letter

Dear Provider:

My name is **Sarah Ann Keil Heinonen** and I am a Doctoral student from **Johns Hopkins University**. I previously contacted you with regard to my **Doctoral Capstone Project** focusing on **Fetal Cardiology** and in doing so I had requested your participation in completing and returning a **knowledge survey about fetal echocardiogram referral indicators**. I also more recently sent you **guideline** information regarding **Fetal Echocardiogram Referrals** and requested you to review the provided information.

I am so grateful for your participation up to this point and now request one last task from you. I would really appreciate it if you would take the time to fill out the final questionnaire regarding **Fetal Echocardiogram Referral Guidelines** as well as **your practices** and **return it in the envelope provided**. Please only return the survey portion of the materials in the provided envelope.

Your participation continues to be voluntary of course and any past and/or future responses you provide will be combined with the information we get from the other participants. Your individual answers will never be disclosed and all information about you will be kept strictly **Confidential**.

I continue to be so very **grateful to you** as well as your **colleagues** whom have been gracious enough to take the time to complete these surveys in the hopes of providing the very best care to all of our patients.

As I mentioned previously and continue to firmly believe that as you have dedicated your life to your chosen career you have an understanding of the importance of this particular topic.

I plan to send out information once all data has been obtained and analyzed to all providers who have participated in this particular survey study. Thanks again for your participation and continued dedication to your field.

If you would like any additional information, please contact (me) **Sarah Ann Keil Heinonen at** -----

-

Sincerely,

Sarah Ann Keil Heinonen, APRN, MSN, C-PNP (DNP Student)

FERP Phase III Factsheet

Study Fact Sheet Fetal Echocardiogram Referral Survey (2)

Who is doing the study?

Myself as a Doctoral Student at Johns Hopkins University in conjunction with the Pediatric Cardiology Division at Loma Linda University Medical Center under the mentorship of Dr. Neda Mulla.

What is Source of Funding?

Currently Myself. This study is not currently funded, and I have no disclosures to make. Grants have been applied for and if funding is obtained that disclosure will be made to all participants.

What is the purpose?

To gain knowledge on referral knowledge and practices of area obstetrical providers for Fetal Echocardiogram and for the benefit of my Capstone Doctoral Project and Dissertation.

How was I selected?

You are noted to be an obstetrical provider in the referral area for Loma Linda University Medical Center and Children's Hospital.

What kinds of questions will be asked?

Questions pertaining only to fetal echocardiogram referral guidelines and practices.

Are my answers confidential?

Absolutely. Your answers will never be used in any way that could be linked to you or your practice. They will be combined with answers from other surveys to create a statistical report and will be tracked only by a reference number.

Do I have to answer?

No. Your help is completely voluntary. Your decision to Participate.

What is the incentive?

Personal and professional support of academic research, knowledge and improved outcomes. You will not be paid for your participation.

**** FERP Phase III Survey and Reminder Cards (Same as Phase I)***

References

- Akbari A., Mayhew, A., Al-Alawi, M. A., et al. (2008). Interventions to improve outpatient referrals from primary care to secondary care. *Cochrane Database Systematic Review*. CD005471.
- American Heart Association. (2010). *Statistics on Congenital Heart defects*. Retrieved from <http://www.americanheart.org/.../heart/1198008486846FS20CCD08.doc>
- Baiardini, I., Braido, F., Bonini, M., Compalati, E., & Canonica, G. W. (2009). Why do doctors and patients not follow guidelines? *Current Opinion in Allergy and Clinical Immunology*, 9, 228-233.
- Beck, S. L. (2002). Strategies to translate research into practice. *Semin Oncol Nurs.*, 18(1), 11-19.
- Cameron, L. (2010). *Most Pregnant Women Never Tested for the Most Common Birth Defect*. *Little Hearts Organization*. Retrieved from http://www.healthnewsdigest.com/news/Women_s_Health_260/Most_Pregnant_Women_Never_Testred_for_the_Most_Common_Birth_Defect.shtml
- Caminiti, C., Scoditti, U., Diodati, F., & Passalacqua, R. (2005, Sep 19). How to promote, improve and test adherence to scientific evidence in clinical practice. *BMC Health Serv. Res.*, p. 62.
- Carlsen, B., Glenton, C., & Pope, C. (2007). Thou shalt versus thou shalt not: a meta-synthesis of GPs' attitudes to clinical practice guidelines. *Br J Gen Pract.*, 57(545), 971-978.
- Chaillet, N., Dubé, E., Dugas, M., Audibert, F., Tourigny, C., Fraser, W. D., & Dumont, A. (2006). Evidence-based strategies for implementing guidelines in obstetrics: a systematic review. *Obstetrical Gynecol.*, 108(5), 1234-1245.
- Children's Hospital Boston. (2010). *Fetal Heart Program*. Retrieved from <http://www.childrenshospital.org/clinicalservices/Site540/mainpageS540P0.html>

- Children's Hospital of DC. (2010). Retrieved from
<http://www.childrensnational.org/DepartmentsandPrograms/default.aspx?type=Program&SubType=ConditionsAndTreatments&SubId=508&SubName=Prenatal%20Support%20Services&Name=Fetal%20Heart%20Program&Id=6023>
- Children's Hospital of Philadelphia. (2010). *Fetal Heart Program*. Retrieved from
<http://www.chop.edu/service/cardiac-center/our-services/fetal-heart-program.html>
- Children's Medical Center. (2010). *Fetal Heart Program*. Retrieved from
<http://www.childrens.com/specialties/template.cfm?groupid=2&pageid=508>
- Cincinnati Children's Hospital. (2010). *Fetal Cardiology Program*. Retrieved from
<http://www.cincinnatichildrens.org/svc/alpha/h/heart-institute/programs/clinical/fetal-cardiology/default.htm>
- Clarkson, J. E. (2004). Getting Research into Clinical Practice - Barriers and Solutions. *Caries Research*, 38, 321-324.
- Congenital Heart defects.com. (n.d.). Retrieved from <http://www.congenitalheartdefects.com/>
- Curran, G. M., Thrush, C. R., Smith, J. L., Owen, R. R., Ritchie, M., & Chadwick, D. (2005). Implementing research findings into practice using clinical opinion leaders: barriers and lessons learned. *Jt Comm J Qual Patient Saf.*, 31(12), 700-707.
- Doherty, S. (2006). Evidence-based implementation of evidence-based guidelines. *International Journal of Health Care Quality Assur. Inc Leadership Health Serv.*, 19(1), 32-41.
- Donaghue, D., & Rychik, J. (2006). The fetal heart program: A multidisciplinary practice model for the fetus with congenital heart disease. *Progress in Pediatric Cardiology*, 22, 129-133.
- Eccles, M. P., & Grimshaw, J. M. (2004). Selecting, presenting and delivering clinical guidelines: are there any "magic bullets"? *Med J Aust.*, 180(6), S52-S54.

- Farmer, A. P., Légaré, F., Turcot, L., Grimshaw, J., Harvey, E., McGowan, J. L., & Wolf, F. (2008). Printed educational materials: effects on professional practice and health care outcomes. *Cochrane Database Systematic Rev.*, 3, CD004398.
- Fletcher, R., Aronson, M., & Sokol, H. N. (2009). *Clinical Practice Guidelines*. Retrieved from www.uptodate.com.
- Forsetlund, L., Bjorndal, A., Rashidian, A., Jamtvedt, G., O'Brien, M. A. et al. (2009). Continuing education meetings and workshops: effects on professional practice and healthcare outcomes (Review). *The Cochrane Collaboration*, 2.
- Forsner, T., Hansson, J., Brommels, M., Wistedt, A. A., & Forsel, Y. (2010). Implementing clinical guidelines in psychiatry: a qualitative study of perceived facilitators and barriers. *BMC Psychiatry*, 10, 8.
- Francke, A. L., Smit, M. A., de Veer, A. J. E., & Mistiaen, P. (2008). Factors Influencing the implementation of clinical guidelines for health care professionals: systematic review. *BMC Medical Informatics and Decision Making*, 8, 38.
- Freemantle, N., Harvey, E. L., Wolf, F., Grimshaw, J. M., Grilli, R., & Bero, L. A. (2007). Printed educational materials: effects on professional practice and health care outcomes. *Cochrane Database Systematic Rev.*, 2, CD000172.
- Germanakis, I., & Sifakis, S. (2006). The impact of fetal echocardiography on the prevalence of live born congenital heart disease. *Pediatric Cardiology.*, 27(4), 465-472.
- Graham, I. D., Beardall, S., Carter, A. O., Tetroe, J., & Davies, B. (2003). The state of the science and art of practice guidelines development, dissemination and evaluation in Canada. *Journal of Evaluation of Clinical Practice.*, 9(2), 195-202.
- Grimshaw, J. M., Eccles, M., Thomas, R., MacLennan, G., Ramsay, C., Fraser, C., & Vale, L. (2006) Toward evidence-based quality improvement. Evidence (and its limitations) of the effectiveness of guideline dissemination and implementation strategies 1966-1998. *J Gen Intern Med.*, 2, S14-S20.

- Grimshaw, J. M., Thomas, R. E., MacLennan, G., Fraser, C., et al. (2004). Effectiveness and efficiency of guideline dissemination and implementation strategies. *Health Technology Assess.*, 8(6), iii-iv, 1-72.
- Grimshaw, J. M., Shirran, L., Thomas, R., Mowatt, G., Fraser, C., et al. (2001). Changing provider behavior: an overview of systematic reviews of interventions. *Med Care*, 39(8), II2-II45.
- Grimshaw, J. M., Eccles, M. P., Walker, A. E., & Thomas, R. E. (2002). Changing physicians' behavior: what works and thoughts on getting more things to work. *Journal Continuing Education Health Prof.*, 22(4), 237-243.
- Grol, R., & Buchanan, H. (2006). Clinical Guidelines: what can we do to increase their use? *Medical Journal of Australia*, 185(6), 301-302.
- Gülmezoglu, A. M., Villar, J., Grimshaw, J., Piaggio, G., Lumbiganon, P., & Langer A. (2004). Cluster randomized trial of an active, multifaceted information dissemination intervention based on The WHO Reproductive health library to change obstetric practices: methods and design issues. *BMC Med Res Methodology*, 4(1), 2.
- Hakkennes, S., & Dodd, K. (2008). Guideline implementation in allied health professions: a systematic review of the literature. *Qual Saf Health Care.*, 17(4), 296-300.
- Hoffman, J. I., Kaplan, S., & Liberthson, R. R. (2004). Prevalence of Congenital Heart Disease. *American Heart Journal*, 147, 425-439.
- Jamtvedt, G., Young, J. M., Kristoffersen, D. T., O'Brien, M. A., & Oxman, A. D. (2006). Audit and feedback: effects on professional practice and health care outcomes. *Cochrane Database Systematic Review.*, 2, CD000259.
- Johnson, B. A., & Ades, A. (2005). Delivery room and early postnatal management of neonates who have prenatally diagnosed congenital heart disease. *Clinical Perinatology*, 32, 921-946.
- Jone, P., & Schowengerdt., K. (2009). Prenatal Diagnosis of Congenital Heart Disease. *Pediatric Clinics of North America*, 56(3).

- Jousimaa, J., Mäkelä, M., Kunnamo, I., MacLennan, G., & Grimshaw, J. M. (2002). Primary care guidelines on consultation practices: the effectiveness of computerized versus paper-based versions. *International Journal Technology Assess Health Care*, 18(3), 586-596.
- Kleinman, C. S. (1995). The responsibilities of the perinatal cardiologist: outcomes analysis. *Ultrasound Obstetrical Gynecology*, 6(6), 380-385.
- Kumar, R. K., Newburger, J. W., Gauvreau, K., Kamenir, S. A., & Hornberger, L. K. (1999). Comparison of outcome when hypoplastic left heart syndrome and transposition of the great arteries are diagnosed prenatally versus when diagnosis of these two conditions is made only postnatally. *American Journal of Cardiology*, 83, 1649-1653.
- Little Hearts Organization. (2010). *Little Hearts Organization*. Retrieved from http://www.littlehearts.org/?utm_source=Google&utm_medium=PPC&utm_content=3&utm_group=Support&utm_link=Home&gclid=CMqN4ruN56ECFRFcbQodQ1TrJw
- Lucille Packard Children's Hospital. (2010). *Fetal Cardiovascular Program*. Retrieved from http://www.ucsfchildrenshospital.org/clinics/fetal_cardiovascular_program/
- Lugtenberg, M., Zegers-van Schaick, J. M., Westert, G. P., & Burgers, J. S. (2009). Why don't physicians adhere to guideline recommendations in practice? An analysis of barriers among Dutch general practitioners. *Implement Sci.*, 4, 54.
- Matchar, D. B., Westermann-Clark, E. V., McCrory, D. C., et al. (2005). Dissemination of Evidence-based Practice Center reports. Agency for Healthcare Research and Quality. *Ann Intern Med.*, 142(12, Pt 2), 1120-1125.
- Medves, J., Godfrey, C., Turner, C., Paterson, M., Harrison, et al. (2009). Practice Guideline Dissemination and Implementation Strategies for Healthcare Teams and Team-Based Practice: a systematic review. *JBIC Library of Systematic Reviews*, 7(12):450-491.
- Mellander, M. (2005). Perinatal management, counseling and outcome of fetuses with congenital heart disease. *Semin Fetal Neonatal Med.*, 10(6), 586-593.

- Newhouse, R. P., Dearholt, S. L., Poe, S. S., Pugh, L. C., & White, K. M. (2007). *Johns Hopkins nursing evidence-based practice model and guidelines*. Indianapolis, IN: Sigma Theta Tau International.
- O'Brien, M. A., Rogers, S., Jamtvedt, G., Oxman, A. D., et al. (2007). Educational outreach visits: effects on professional practice and health care outcomes. *Cochrane Database Systematic Rev.*, 4, CD000409.
- O'Brien, M. A., Oxman, A. D., Davis, D. A., Haynes, R. B., Freemantle, N., & Harvey, E. L. (2007). Audit and feedback versus alternative strategies: effects on professional practice and health care outcomes. *Cochrane Database Systematic Review*, 1, CD000260.
- Ockene, J. K., & Zapka, J. G. (2000). Provider education to promote implementation of clinical practice guidelines. *Chest*, 118(2), 33S-39S.
- Prior, M., Guerin, M., & Grimmer-Somers, K. (2008). The effectiveness of clinical guideline implementation strategies--a synthesis of systematic review findings. *Journal of Evaluation of Clinical Practice*, 14(5), 888-897.
- Sammer, C. E., Lykens, K., & Singh, K. P. (2008). Physician characteristics and the reported effect of evidence-based practice guidelines. *Health Service Res.*, 43(2), 569-581.
- Schectman, J. M., Schroth, W. S., Verme, D., & Voss, J. D. (2003). Randomized controlled trial of education and feedback for implementation of guidelines for acute low back pain. *Journal of General Internal Medicine*, 18(10), 773-780.
- Sharland, G. (2009). Fetal Cardiac Screening; why bother? *Archives of Disease in Childhood*. Published online 17 August 2009; doi: 1136/adc.2008.15122.
- Smith, W. R. (2000). Evidence for the effectiveness of techniques to change physician behavior. *Chest*, 118(2), 8S-17S.
- Solberg, L. I. (2000). Guideline implementation: what the literature doesn't tell us. *Jt Comm J Quality Improvement*, 26(9), 525-537.

Solucient. (n.d.). Retrieved from

http://thomsonreuters.com/products_services/healthcare/cardiovascular.aspx

Stone, T. T., Schweikhart, S. B., Mantese, A., & Sonnad, S. S. (2005). Guideline attribute and implementation preferences among physicians in multiple health systems. *Qual Manag Health Care, 14*(3), 177-187.

St-Pierre, I., Davies, B., Edwards, N., & Griffin, P. (2007). Policies and Procedures: A Tool to Support the Implementation of Clinical Guidelines. *Nursing Leadership, 20* (4), 65-80.

University of Michigan Health System. (2007). For Babies With Heart Defects, Death Risk Is Far Lower At Most Experienced Hospitals. *ScienceDaily*. Retrieved from <http://www.sciencedaily.com/releases/2007/12/071217092926.htm>.

Van den Berg, M. J., Bakker, D. H., Spreewenberg, P., et al. (2009). Labour intensity of guidelines may have a greater effect on adherence than GP's workload. *BMC Family Practice, 10*, 74.

Verheijen, P. M., Lisowski, L. A., Stoutenbeek, P., Hitchcock, J. F., Brenner, J. I., Copel, J. A., et al. (2001). Prenatal diagnosis of congenital heart disease affects preoperative acidosis in the newborn patient. *Journal of Thoracic and Cardiovascular Surgery, 121*, 798-803.

Wright, J., Warren, E., Reeves, J., Bibby, J., Harrison, S., Dowswell, G., Russell, I., & Russell, D. (2003). Effectiveness of multifaceted implementation of guidelines in primary care. *J Health Service Res Policy, 8*(3),142-148.

Wright, R. W., Brand, R. A., Dunn, W., & Spindler, K. P. (2007). How to Write a Systematic review. *Clinical Orthopedics and Related Research, 455*, 23-29.

Zwarenstein, M., Goldman, J., & Reeves, S. (2009). Interprofessional collaboration: effects of ASAS practice-based interventions on professional practice and healthcare outcomes. *Cochrane Database Systematic Rev, 3*, CD000072.