

Early Check: Pathways of Awareness

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Dedication

To my father, William ... I wish you were here to see what your little girl has become. I'd like to think that I would have made you proud. I miss you terribly and I hope that one day I'll see you on the other side. I love you, Honey.

Abstract

The Early Check study offers free expanded newborn screening for Fragile X syndrome and spinal muscular atrophy to all pregnant women in North Carolina that sign up between 13 weeks gestation and four weeks postpartum. Disseminating information to the public about the Early Check program is imperative to its success in identifying affected children and connecting them with the resources needed for early intervention. This project was undertaken with the goal of increasing the knowledge of OB/GYN providers and their ancillary staff regarding Early Check to enable them to answer patient questions about the program. OB/GYN practices in nine counties of North Carolina were contacted via phone and email for participation in brief education sessions about Early Check. Of 42 practices contacted, ten responses were received with seven practices participating in education sessions and eight practices agreeing to disseminate flyers to their patients. Outreach to OB/GYN practices was minimally successful, but the effects of collaboration with the small number of participants were significant. This intervention alone has the potential to reach more than 8,000 women each year. Collaborating with OB/GYN practices shows promise for current and future health initiative information dissemination targeted to pregnant and newly postpartum women.

Key words: Early Check, dissemination, health initiative, OB/GYN, Fragile X syndrome, spinal muscular atrophy

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1 **Chapter One: Overview of the Problem of Interest**

2 Fragile X syndrome (FXS) and spinal muscular atrophy (SMA) are both rare genetic
3 disorders that can affect the health, mental well-being, and quality of life for newborns and their
4 parents (Research Triangle Institute International [RTI International], 2019). Currently, these
5 conditions are not included in the newborn screening panel in any of the 50 states. SMA was
6 recently added to the recommended screening panel by the Department of Health and Human
7 Services, but the decision to include it in the North Carolina panel is still pending (Haelle, 2018).
8 Fragile X syndrome has been evaluated but, thus far, has not made it into the United States
9 recommended screening panel.

10 The Early Check program in North Carolina has gained momentum since its launch in
11 2018 and offers a temporary solution to the lack of screening for infants with these conditions
12 (RTI International, 2018). Currently, the Early Check program offers an optional genetic
13 screening requiring mothers to “opt-in” to have screening for FXS and SMA added to their
14 newborns’ screening labs (RTI International, 2019). Mothers can opt-in after the first trimester of
15 pregnancy and before four weeks postpartum (RTI International, 2019). The hope for the future
16 is the inclusion of FXS and SMA to the current state newborn screening panel, but there is much
17 to do before this happens. For this program to be successful and reach its potential, the parent
18 population must be aware of what it is, what it does, and who can participate. Therefore, the
19 purpose of this project was to determine an effective method of information dissemination that
20 could increase the awareness about the Early Check program among the pregnant or immediately
21 postpartum population in the Triad region of North Carolina.

22 **Background Information**

23 Fragile X syndrome is the most common inherited genetic disorder that results in
24 intellectual and developmental disabilities. The syndrome results from inactivation of the FMR1
25 gene and presents in a wide variety of clinical signs and symptoms. Patients with FXS often
26 present with physical manifestations such as facial elongation, enlarged ears, hypermobility of
27 joints, muscular hypotonia, mitral valve prolapse, and macroorchidism (Neri, 2017). Other
28 manifestations are not as visible and include epilepsy, intellectual disability, and behavioral
29 problems such as gaze avoidance, echolalia, hyperactivity, and attention deficit that may be
30 mistaken for autism spectrum disorder (Neri, 2017). While the previous manifestations are
31 characteristic of a full mutation of the FMR1 gene resulting in FXS, there are even more children
32 that are carriers of the premutation gene. These children are at risk for the development of
33 specific health issues later in life, namely premature ovarian failure and fragile X tremor/ataxia
34 syndrome (Neri, 2017). Symptoms affect males more frequently than females and are usually
35 more severe as females have two copies of the X chromosome and less likelihood of receiving
36 both as mutations. The prevalence of FXS is questionable due to the current lack of screening
37 and the difficulty of accurate diagnosis. The full mutation is thought to affect approximately 1 in
38 4000 males and approximately half that number in females while the premutation is estimated to
39 affect as many as 1 in 148 females and 1 in 290 males (Centers for Disease Control and
40 Prevention, 2018; Pyeritz, 2019). Diagnosis of FXS usually occurs after many long months of
41 searching for the cause of children's symptoms and diagnosis can take around three to four years
42 to discover depending on gender (Centers for Disease Control and Prevention, 2018).

43 Spinal muscular atrophy (SMA) is an inherited disease affecting the lower motor neurons
44 of the body and is the most common single-gene cause of infant death (National Institute of
45 Neurological Disorders and Stroke [NINDS], 2018). In this condition, the lower motor neurons

46 that control walking, eating, speaking, and even breathing begin to degenerate, causing
47 disruption in nerve impulses and functional failure. There are several types of SMA; each
48 affecting different age ranges with varying degrees of severity. Of greatest concern is SMA type
49 1, also known as infantile-onset SMA (NINDS, 2018). This type of SMA is clinically notable
50 with signs and symptoms presenting by six months of age that rapidly progress, causing
51 respiratory failure and death by the age of two years (NINDS, 2018). This devastating genetic
52 disorder affects approximately 1 in 10,000 babies born in the United States with potentially more
53 that are unaccounted for as they develop symptoms later in life (Lally et al., 2017).

54 Children suffering from FXS and SMA represent a small percentage of the United States
55 population but present a tremendous impact in terms of healthcare burden. Children with FXS
56 require frequent monitoring and intervention for the management of seizure and mood disorders,
57 as well as interventions by speech, physical, occupational, and psychological therapists (Van
58 Esch, 2019). The economic burden for families with children with FXS becomes an issue as
59 these children have moderate intellectual disabilities, leaving them incapable of independence.
60 Most of the economic burden for these families revolves around healthcare expenses not covered
61 by medical plans, lost work productivity, cost of informal caregivers, and indirect care costs
62 (Sacco, Raspa, Leahy, & Cabo, 2018). In addition to the medical and economic burden that FXS
63 brings to families, there is the unmeasurable psychological and emotional stress that comes with
64 parenting a special needs child. These stresses are only exacerbated by feelings of guilt, grief,
65 and helplessness that accompany the loss of the expected normal childhood.

66 In children with SMA, the medical management required is extensive and involves
67 nutritional and feeding support, frequent pulmonary hygiene interventions, physical therapy and
68 bracing, and management of gastrointestinal and respiratory complications (Bodamer, 2019). As

69 SMA is a progressive disorder, the costs associated with it increase exponentially as time passes.
70 Like FXS, SMA also carries with it the economic burden from lost productivity, out-of-pocket
71 health care costs, informal caregiver expenses, and indirect care costs. The emotional and
72 psychological ramifications are perhaps more taxing in SMA because of the progressive and
73 terminal nature of the condition. Anticipatory grief, guilt, and feelings of hopelessness and
74 helplessness are all part of parenting a child with SMA as approximately 68% of these children
75 will die before the age of two years, and 82% will die before the age of four years (SMA News
76 Today, 2019).

77 Communication of information about Early Check is essential in increasing parental
78 awareness of the options for testing their children prior to the manifestation of symptoms. For
79 years, different strategies have been amassed for communicating health initiatives with no one
80 way of sharing information being designated as the most effective. In the current medical
81 climate, numerous ways of promoting awareness have been used successfully. These include the
82 development of written materials such as brochures, newspaper articles, pamphlets, and flyers as
83 well as digital resources such as videos, social media groups, television broadcasts, radio
84 commercials, and advertisements on cell phone applications (Rural Health Information Hub,
85 2015). No matter what communication strategy is used, it must be targeted to the population in
86 question and the various health literacy levels within it in order to be successful.

87 Experts involved in the Early Check program have been searching for a successful way to
88 increase parental awareness in North Carolina since its inception in 2018. The program approach
89 has encompassed several phases, with each involving a different form of information sharing.
90 Initial phases included the creation of flyers for providers and parents along with an invitation
91 letter mailed to expectant moms in North Carolina (RTI International, 2019a). Later phases

92 included postcards and a social media page to evaluate their efficacy for information
93 dissemination. This is a great start, but there are many ways to increase awareness that have not
94 been evaluated.

95 **Significance of Clinical Problem**

96 For several years, both FXS and SMA have been considered for inclusion in newborn
97 screening tests but were rejected because there were no reliable tests or effective treatments
98 available (Kemper, 2019). With technological and scientific advances, there is now cost-effective
99 testing available for both disorders and promising treatments that may reduce the severity of
100 symptoms. Nusinersin, an intrathecal or intraspinal injection, has shown promise in helping
101 symptomatic children with SMA reach motor milestones with an average effectiveness of 51%
102 (Bodamer, 2019). In children with FXS, several trials have studied the effects of Lithium,
103 Minocycline, gamma-aminobutyric acid (GABA) system agonists, and metabotropic glutamate
104 receptor 5 (mGluR5) antagonists with varying results showing improvement in behavior,
105 memory, and adaptive capabilities (Van Esch, 2019).

106 Thanks to the federal and private grants that were awarded to the Early Check program,
107 cost is no longer a concern. Parents have the opportunity to opt-in for genetic testing for both
108 FXS and SMA using the newborn screening blood spot sample already used for the North
109 Carolina state screening panel at no charge (RTI International, 2019). Increasing parental
110 awareness of the effects of FXS and SMA, the importance of early identification and
111 intervention, and the existence of the Early Check program may help to increase the number of
112 newborns screened. There are several routes through which parents may be exposed to this
113 information, but awareness prior to the birth of the child has excellent potential for increasing
114 newborn screening opt-in. It is the hope that identifying infants with these disorders prior to the

115 presentation of clinical symptoms will assist in providing early intervention to maximize the
116 quality of lives of the affected children and families, develop comprehensive treatment plans,
117 optimize developmental and intellectual functioning for FXS, and optimize physical functioning
118 for SMA to reduce both familial and healthcare burden. As OB/GYN providers and staff are in a
119 prime position to answer questions and share information about the Early Check program, the
120 intervention targeted increasing their awareness through lunch and learn activities held in local
121 OB/GYN offices.

122 **Question Guiding Inquiry (PICO)**

123 As the Triad area of North Carolina serves as a hub for obstetrical care and delivery for
124 women from surrounding counties, there was an interest in increasing OB/GYN provider's
125 knowledge of the Early Check program and their ability to disseminate accurate program
126 information to pregnant patients or patients in the immediate post-partum period.

127 **Population.** The population targeted in this project was the OB/GYN physicians,
128 advanced practice providers, and clinic nurses at five different obstetrical care offices in Forsyth
129 County, North Carolina.

130 **Intervention.** Lunch and Learn events were planned to provide education to OB/GYN
131 providers about the FXS, SMA, and the Early Check program. Each provider was invited to
132 include a parent educational flyer about Early Check in prenatal visits at 36-40 weeks gestation.
133 The flyer included a brief overview of the Early Check program with a QR code for increased
134 convenience of access via smartphone.

135 **Comparison.** While there were no known processes of promoting patient knowledge of
136 Early Check in OB/GYN offices, the goal was to have at least three out of five offices participate
137 in the lunch and learn.

138 **Outcome(s).** Providers would use the knowledge gained during the lunch and learns to
139 discuss Early Check with patients and answer parents' questions about the program. With
140 increased awareness, participation in the Early Check program may increase, thereby increasing
141 the number of affected infants identified and the implementation of early interventions and
142 treatments.

143 **Summary**

144 In conclusion, FXS and SMA are both inherited disorders detectable at birth by new
145 testing methods developed as the result of technological advances. FXS is the number one
146 genetic cause of intellectual disability and affects children in a wide variety of ways. Most of
147 these children suffer from seizure disorders, intellectual disability, and developmental delays of
148 varying degrees. The medical and economic burden resulting from the management of FXS can
149 be difficult to imagine for those with children not affected by the disorder. In prior years, FXS
150 has been in the running for inclusion in the newborn screening panel, but it has never made the
151 cut due to the lack of affordable testing and the lack of effective treatment. Fortunately, with the
152 advances in technology, new and potentially effective treatments are being trialed with
153 promising results to help manage, if not cure, the disorder.

154 Like FXS, SMA has been included in the running for inclusion in the statewide newborn
155 screening panel. As the leading single-gene inherited disorder responsible for the most infant
156 deaths, SMA is undoubtedly worthy of attention. Previously, the inability to meet screening
157 criteria requiring cost-effective testing and treatment resulted in its exclusion from the state
158 screening panel. With the recent mapping of the human genome and the advances surrounding
159 genetic testing, it is now feasible to test for SMA on a population-wide basis. Along with that

160 accomplishment, there have been clinical trials regarding the use of Nusinersin in children in the
161 symptomatic stage that have shown promise in at least half of cases.

162 With both FXS and SMA meeting the testing criteria and having the promise of early
163 intervention treatments, the timing was optimal to reevaluate the necessity of their inclusion in
164 the statewide newborn screening panel. As part of this process, the Early Check program has
165 been put in place to offer parents the opportunity to opt-in to the testing using the newborn
166 screening blood sample gathered after birth. With this opportunity to opt-in readily available, it
167 was beneficial to determine if OB/GYN providers are a valid route for information dissemination
168 about the Early Check program.

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183 **Chapter Two: Review of the Literature**

184 To determine the current policies, procedures, and knowledge surrounding FXS, SMA,
185 Early Check, and communication of health initiatives, it was necessary to consult the available
186 literature. Chapter Two encompasses the literature review process and results found using
187 databases and appropriate internet resources. A discussion of findings and opportunities for
188 further research is included in this chapter.

189 **Literature Appraisal Methodology**

190 **Sampling strategies.** A literature search was completed using the East Carolina
191 University Laupus Library OneSearch and PsycINFO databases. Search terms included Fragile X
192 syndrome, spinal muscular atrophy, newborn screening, Early Check, population, health, health
193 initiatives, and public communication. Using PsycINFO, the search terms population, health, and
194 health initiatives with appropriate Boolean operators as indicated returned 909 results with seven
195 chosen for inclusion. The terms population health and public communication provided 24 results
196 with three chosen for inclusion. Using OneSearch, the terms Fragile X syndrome and newborn
197 screening resulted in 920 articles with seven chosen for inclusion. The terms spinal muscular
198 atrophy and newborn screening provided 761 results with six included for use in this project. The
199 search term of “Early Check” was further limited by the designation of medicine and produced
200 43 articles, three of which were pertinent. Other resources, including websites and professional
201 agency internet pages, were added, resulting in 42 articles or resources for review.

202 **Evaluation criteria.** Inclusion criteria required the articles to be pertinent to the project
203 purpose, informational, or evidence-based. Only articles and resources published within the last
204 five years were included except for one original article that was very pertinent to the topic for the
205 DNP project. Articles included were from scholarly and peer-reviewed journals or internet

206 resources from professional organizations. All articles and resources were written in the English
207 language and were available in full-text versions. Most included references originated from the
208 United States in order to help with the transferability of findings.

209 Articles were excluded for several reasons, including those based on genetics and in-
210 depth testing methods, which were excluded for both conditions. Duplication of articles was
211 excluded to reduce redundancy. Articles that were published more than five years prior or that
212 were not scholarly or peer-reviewed were excluded. Further exclusion was considered if the
213 article did not pertain to the specific purpose and goal of the project. Resources that pertained to
214 other conditions or medical concerns were excluded unless they provided information that
215 supports the rationale and need for the proposed DNP project concept or intervention. Articles
216 that were written in languages other than English or originating outside the United States were
217 excluded unless directly related and useful to the project. Articles and resources that were of
218 lower evidence levels were excluded unless they specifically pertained to the project.

219 Levels of evidence for all included articles and resources are as follows: Level I (14),
220 Level II (0), Level III (3), Level IV (6), Level V (3), Level VI (6), and Level VII (10). Websites
221 from professional agencies were included as Level VII evidence due to their informational nature
222 from expert sources.

223 **Literature Review Findings**

224 Evidence found in the literature was formulated from a variety of sources. Approximately
225 33% of the literature reviewed was in the form of systematic reviews, meta-analyses, or clinical
226 guidelines that were based upon research findings and best-practice. An estimated 24% of
227 sources were obtained from expert opinions and professional agency documents. Nearly 14% of
228 the literature was from case-controlled or cohort studies, and an additional 14% was from single

229 descriptive studies or qualitative studies. The remaining literature was from controlled
230 nonrandomized trials and systematic reviews of descriptive and qualitative studies.

231 **Fragile X syndrome.** Fragile X syndrome is a genetic disorder that is responsible for
232 most genetically-related intellectual disabilities in children. Many children affected by FXS are
233 diagnosed as autistic due to their clinical presentation and behaviors (Pyeritz, 2019). The
234 condition has been well researched with a focus on symptom manifestations, physical
235 characteristics, and overall caregiver burden that accompanies having a child with FXS. There
236 are multiple trials in progress that are testing potential treatments and medications that may have
237 a positive impact on children with FXS. These trials have suggested many different drugs be
238 used off label for the treatment of the mental and physical deficits associated with the condition
239 (Van Esch, 2019). Several of these trials are showing the potential to reduce symptoms, optimize
240 performance, improve quality of life, and reduce healthcare and caregiver burden. One such
241 study is NeuroNEXT, a clinical trial to evaluate the effectiveness of a medication referred to as
242 AFQ056 on developmental functioning in children with FXS (United States National Library of
243 Medicine, 2018).

244 Gaps in the literature related to FXS can be found in specific areas. Due to a lack of
245 standardized screening and the difficulty of accurate and timely diagnosis, the prevalence of FXS
246 cannot be accurately established for either the full mutation or the premutation. There are few
247 resources available outlining actual life expectancy for those with FXS. Most available
248 information points to a normal expected lifespan but does not account for any disease-specific
249 complications that may cause early death. Caregiver burden has not been well-researched despite
250 the information available detailing the high costs of care and the burden on healthcare systems
251 (Sacco et al., 2018). Screening ethics regarding testing of blood relatives has been discussed, but

252 there have been no ethical conclusions or processes developed to allow for cascade screening.
253 Ethical aspects of screening will undoubtedly be a consideration brought up by the target
254 population in the implementation of the proposed DNP project intervention.

255 **Spinal muscular atrophy.** Research on the condition of SMA has been plentiful, and
256 there is much known about the condition, its progression, symptom manifestations, and mortality
257 rates. There are large amounts of literature concerning the genetic alteration in these children and
258 the research that is being done to develop more significant treatments that will allow for
259 symptom reduction, delayed age of onset, and reduction in the severity of the disease course.
260 Treatments such as Nusinersin are being used to successfully treat approximately half of the
261 children affected while other methods are still in trial stages (Bodamer, 2019). NeuroNEXT is
262 also supporting clinical research for further investigation into clinical genetic markers, or
263 biomarkers, that can allow for assessment of the predictive value of the severity of the disease in
264 a child and the actual effectiveness of an intervention (United States National Library of
265 Medicine, 2018a). General information on supportive care and available resources for the care of
266 a child with SMA is readily available on several of the professional agency websites.

267 Gaps in available literature are similar to those noted for FXS. Due to the earlier onset of
268 more specific symptoms and the more precise nature of the diagnosis, SMA is often tested for
269 much earlier than FXS (National Human Genome Research Institute, 2012). Like FXS, costs
270 and burdens of the disease have been discussed, yet there is little detail on the specific healthcare
271 impact or emotional toll involved in caring for a child with SMA. Little information has been
272 published on the prevalence of the disease in terms of race, gender, or ethnicity; many resources
273 state that any race or gender may be affected (Hendrickson et al., 2009; Verhaart et al., 2017).
274 Due to the short lifespan of many of the children with this disease, there are few actively

275 recruiting long-term studies to determine the efficacy of clinical trials for symptom management
276 (TREAT-NMD Neuromuscular Network, 2019). While these gaps do not specifically impact the
277 proposed DNP project intervention, they are essential areas of consideration. Parents will
278 undoubtedly ask questions with less than definite answers, indicating the need for future
279 research.

280 **Newborn screening.** Newborn screening began in the 1960s and has helped to prevent
281 millions of infant deaths in the decades since (Ulph et al., 2017). Newborn screening is
282 performed in every state as a required participation program; however, some states allow parents
283 to opt-out for religious or personal reasons (Association of Public Health Laboratories, 2013).
284 There are many different conditions tested for using a single blood spot obtained through a heel
285 stick within 24-48 hours after birth (Association of Public Health Laboratories, 2013). Using this
286 blood spot, tests are completed to determine the presence of health conditions that require early
287 intervention in order to limit the severity of symptoms and associated complications. Though
288 there is a national panel available for recommended newborn screening tests called the
289 Recommended Uniform Screening Panel (RUSP), each state determines its panel of tests
290 (Kemper, 2019). In 2018, the development of potentially effective treatments and cost-effective
291 testing secured SMA a place on the national recommendation list but, at this time, it has not been
292 added to any state panels (Kemper et al., 2018). FXS has been considered for inclusion on the
293 RUSP, but the lack of potentially effective treatments, valid and inexpensive testing, and
294 feasibility studies have been barriers to its addition to the list (Okoniewski et al., 2019).

295 A small volume of literature surrounding parental and provider attitudes regarding
296 newborn screening was available. Surveys of the general population have shown that more than
297 80% of individuals are favorable to screening newborns for genetic diseases, even if there are no

298 readily available treatments or cures (Boardman & Sadler, 2017). Approximately 85% of
299 physicians are not willing to discuss newborn screening with their patients for reasons specified
300 as lack of time and little financial compensation (Hayeems et al., 2009). Of all the provider
301 categories included in this study, midwives were found to be far more receptive, with 90%
302 sharing information about newborn screening with their patients (Hayeems et al., 2009).

303 Gaps in information regarding newborn screening were not readily found due to the
304 intense research and attention given to the process over the past decades. Most gaps noted in the
305 literature involving newborn screening centered on parent education (Botkin, Rothwell, &
306 Anderson, 2016). Parental knowledge about newborn screening is lacking, with one study
307 showing that greater than 40% of pregnant women are not aware of newborn screening until the
308 postpartum period (Newcomb et al., 2013). Education regarding newborn screening is not a
309 routine part of most OB/GYN visits, and the immediate postpartum visit presents challenges in
310 ensuring understanding of screening purposes and procedures (Newcomb et al., 2013).

311 **Early Check.** Early Check is a voluntary newborn screening expansion program that
312 allows parents to opt-in to have their baby tested for FXS and SMA. The researchers involved in
313 the Early Check program have published articles revolving around early identification and
314 intervention and the effects that it may have on children suffering from either condition (Bailey
315 et al., 2017). Beyond the expansion of newborn screening, Early Check has referral measures in
316 place for families of children that screen positive for either disorder, increasing connections to
317 resources for further testing, community-based resources, and possible interventions or
318 treatments (Bailey et al., 2017). Since the program launched in the Fall of 2018, Early Check has
319 screened thousands of newborns for the two conditions (RTI International, 2019). Researchers
320 affiliated with Early Check have evaluated parental interest in additional newborn screening and

321 efficacy of information sharing via invitation letters and in-hospital education (Bailey et al.,
322 2017). There were no specific gaps identified in the literature about the Early Check program as
323 the initiative is still in the development and implementation phases.

324 **Information dissemination of public health initiatives.** Literature regarding
325 information dissemination of health initiatives to the public is limited. There are several studies
326 available that discuss the implementation of health initiatives, but few that are directed to similar
327 subject matter. Overall, it has been found that dissemination of information geared toward
328 program or initiative success depends on the community involved, the inclusion of key
329 individuals, continued involvement of stakeholders, trusting work relationships, and a perceived
330 benefit of participation (Taylor et al., 2017). There are several principles that have been
331 determined to aid in successful promotion and integration of public health initiatives including
332 sharing of data, collaboration in analysis, sustainability of the program, community engagement
333 in determination of population health needs, shared goals, and leadership aligned with population
334 health improvement (Kuo, Thomas, Chilton, & Mascola, 2018). Other research has determined
335 that successful change involving public health initiatives needs an expanded team composition,
336 frequent site visits, shared interests, and trust development to promote participation (Loehrer,
337 McCarthy, & Coleman, 2015).

338 One of the few studies that closely aligned with the proposed intervention of this project
339 was a systematic review of literature dealing with under-screened populations and successful
340 intervention through public health communication (Jones, Ross, Cloth, & Heller, 2015). This
341 review found that partnership with community organizations, local businesses, governments, and
342 lay health workers was shown to significantly improve the reach of screening activities (Jones et
343 al., 2015). Tailored interventions, or interventions designed to be flexible to account for cultural,

344 educational, or knowledge-based concerns, were less effective in reaching under-screened
345 individuals, yet still modestly improved awareness and participation (Jones et al., 2015). The
346 promotion of patient awareness of screening opportunities is integral in promoting program
347 participation. Some studies have evaluated the best timing for information sharing. One such
348 study evaluated the most effective method and timing of information sharing surrounding
349 newborn screening (Ulph et al., 2017). This study found that the optimal time for sharing
350 information with parents was in the third trimester of pregnancy, noting that parents were less
351 likely to forget to ask questions and more likely to conduct personal research about newborn
352 screening when information is presented shortly before giving birth (Ulph et al., 2017).

353 The most effective form of information dissemination to the public has been debated in
354 recent years with the development of technology and the widespread use of social media and the
355 internet. Social media has provided endless opportunities for research and a broadened reach to
356 subjects not otherwise engageable by traditional means, but there have been ethical concerns
357 raised regarding confidentiality, privacy, and authenticity (Hunter, Gough, O'Kane, McKeown,
358 & Fitzpatrick, 2018). Social media is promising as a means for disseminating information to a
359 maximum number of people, but more investigation is needed to evaluate its efficacy. Other
360 methods of information dissemination include television and newspaper ads, letters, postcards,
361 word-of-mouth, and digital ads. Any of these methods can, and have, been useful in information
362 sharing, but no one method is considered the best as each target audience and health message
363 must be taken into account to facilitate success in spreading the message effectively (Rural
364 Health Information Hub, 2015).

365 **Limitations of the Literature Review Process**

366 The literature review process was limited by the overabundance of information related to
367 the genetic considerations for FXS and SMA, as well as the lack of information surrounding
368 parental experiences, burden analysis, and communication of public health information.
369 Literature specifically targeted at dissemination of health care initiatives is sparse, and as such,
370 there was difficulty finding adequate references to support the proposed project intervention.
371 Limitations on barriers to screening were evident with many articles discussing the need for
372 screening yet failing to indicate the reasons parents identified when choosing not to participate in
373 available newborn screening initiatives (Paquin, Peay, Gehtland, Lewis, & Bailey, 2016; Phan,
374 Taylor, Hannon, & Howell, 2015; Tarini, Simon, Payne, Gebremariam, & Rose, 2018; Ulph et
375 al., 2017). Finally, there is minimal literature available on the participation rates, efficacy, and
376 cost-effectiveness of specific communication efforts for newborn screening programs.

377 **Discussion**

378 **Conclusion of findings.** Newborn screening is a state program with required
379 participation unless parents decline for personal or religious reasons (Association of Public
380 Health Laboratories, 2013). Newborn screenings evaluate for a specific panel of genetic and
381 metabolic conditions that can cause severe or fatal outcomes for affected children (CDC, 2019).
382 FXS and SMA are conditions that can negatively impact children and families. There is current
383 discussion about including both disorders on newborn screening panels in numerous states and
384 nations but, to date, they have not met the criteria due to the lack of cost-effective testing,
385 effective treatments, and feasibility studies (Boardman & Sadler, 2017; Okoniewski et al., 2019).
386 Given the lack of a documented successful treatment, there are many who do not believe the
387 conditions should be included (Dimmock, 2017). Despite this, the majority of the general
388 population prefers to know about the presence of such genetic conditions even without the ability

389 to cure the disorders (Tarini et al., 2018). Both conditions can be detected by current screening
390 methods utilizing the blood spot collected shortly after birth for newborn screening (North
391 Carolina Department of Health and Human Services, 2018). Supplemental screening is available
392 to parents in North Carolina through a program called Early Check. Parents can opt-in to the
393 additional newborn screening tests during the second and third trimesters of pregnancy and up to
394 four weeks of the newborn's life. Parental awareness of Early Check is needed to increase
395 participation in the Early Check program. Methods of increasing parental awareness of screening
396 vary widely, but the effectiveness of each form of communication is unknown. Research is
397 lacking regarding effective forms of information dissemination; further investigation into
398 successful strategies for dissemination is needed. Some research has concluded that involving the
399 community and ensuring trusting relationships is key to successful information dissemination. As
400 providers, OB/GYNs require trust and patient involvement in order to provide optimal care and
401 promote positive outcomes (Birkhauer et al., 2017). Thus, the proposed intervention involved
402 utilizing this trust to promote both provider and parent awareness of the Early Check program.
403 While some prior research found that OB/GYN physicians were uninterested in educating
404 patients regarding newborn screening, there are other providers that work in conjunction with
405 them that may be more willing to share information with parents and answer questions (Hayeems
406 et al., 2009). Improving provider awareness, including nurse practitioners, midwives, physician
407 assistants, physicians, and clinical nurses, can increase clinicians' ability and willingness to
408 answer parents' questions and create a process for disseminating information about newborn
409 screening as the new standard of care. The proposed intervention was to visit OB/GYN offices in
410 the Forsyth County area of North Carolina to disseminate information about Early Check, FXS,
411 SMA, and newborn screening to providers using a lunch and learn format. Each site was asked to

412 participate in promoting parental awareness of Early Check by including a parent education flyer
413 during one routine prenatal visit between 36- and 40-weeks gestation. The goal of the DNP
414 project was to increase awareness and participation in optional newborn screening so that early
415 identification of FXS or SMA can be made and interventions can be offered. Information
416 gleaned from expanded newborn screening could be used to improve the lives of affected
417 children and their families.

418 **Advantages and disadvantages of findings.** Promoting the awareness of Early Check
419 was the most apparent advantage of the proposed project. Increased awareness can bring about
420 increased participation and early diagnosis of FXS and SMA. Early identification can reduce the
421 negative impacts of FXS and SMA on the lives of children and their families through early
422 treatment and supportive measures. Further advantages lie in the promotion of trusting
423 relationships between parents and providers. Improved population knowledge and awareness of
424 these disorders are advantages and may help to make a positive impact on the population such as
425 improved diagnostic accuracy to reduce parental and family stress, and development of school
426 programs for management of FXS and SMA. Community advantages include the awareness of
427 the special needs of children affected by FXS and SMA such as daycare accommodations,
428 inclusion programs such as Special Olympics, and additional community resources. Furthermore,
429 information on the effectiveness of the forms of dissemination of population health information
430 and initiatives can help to develop best practice in information dissemination methods for future
431 health initiatives.

432 Disadvantages of engaging providers to disseminate health information such as Early
433 Check included that providers are short on time and overwhelmed with existing mandatory
434 policies and procedures. The willingness of the provider or the ancillary staff to participate in the

435 DNP project intervention was a critical factor in their participation in the lunch and learn
436 provider education sessions and subsequent dissemination of optional newborn screening
437 opportunities to parents. Given the limited timeframe of the project, there was the potential
438 inability to include other obstetrical and newborn care providers that could be great resources for
439 information dissemination. The education flyer was able to reach the majority of pregnant
440 patients but did not apply to patients with learning disabilities, low education levels, and those
441 who do not speak English or Spanish. Finally, the institutional policies had the potential to not
442 allow for the inclusion of educational material outside of what is developed and contracted for in
443 their practice.

444 **Utilization of findings in practice change.** Implementation of the proposed intervention
445 involved the identification and willingness to participate of potential OB/GYN offices for the
446 lunch and learn activities. Once practices were identified as potential participants, the student
447 project leader approached the practice to secure a date for the lunch and learn. The lunch and
448 learn included clinical staff in OB/GYN offices, including physicians, nurse practitioners,
449 certified nurse midwives, physician assistants, clinical nurses, laboratory staff, and other clinical
450 staff. Including all clinical staff was an effort to increase the awareness of the office as a whole.
451 This method of information dissemination about the Early Check initiative and the associated
452 disorders had the potential to reset the standard of care for prenatal visits between 36- and 40-
453 weeks gestation through a clinical culture shift that included all clinicians in the practice working
454 together to discuss the new screening possibilities with families. Increasing providers' awareness
455 and developing a format of information dissemination that is streamlined and time-conscious
456 could positively impact the parental awareness of Early Check and increase optional newborn
457 screening participation. While there was no available literature to support this intervention, there

458 were findings that the trusting relationship between pregnant women and their providers could be
459 used to disseminate public health initiatives successfully (Birkhauer et al., 2017).

460 **Summary**

461 Implementation of this project served to meet the needs of the population to both increase
462 awareness and overall health. Promoting information regarding pre-symptomatic screening of
463 infants for FXS and SMA may help to initiate early intervention and prevent some of the costly
464 care necessary in those that progress through the course of the disorder after symptoms appear.
465 Early interventions for FXS and SMA serve to meet the goals of Healthy People 2020 by
466 improving quality of life, minimizing the degree of disease-related disability, preventing
467 premature death, promoting healthy behaviors, and promoting good overall health (Centers for
468 Disease Control and Prevention, 2014). Early interventions are not possible without appropriate
469 screening and early identification, requiring that parents be made aware of the available
470 programs and services. Involving clinical partners in OB/GYN practices in Forsyth County,
471 North Carolina, to assist in disseminating the availability of Early Check is one method for
472 increasing participation in optional newborn screening. Increased participation can help to
473 provide a more accurate understanding of prevalence for each condition and a greater awareness
474 of strengths and barriers in caring for children diagnosed with FXS or SMA.

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481 **Chapter Three: Theory and Concept Model for Evidence-based Practice**

482 Concept analysis, theoretical framework, and change models are essential parts of a DNP
483 project and help drive the innovation and plan the implementation of change. This chapter
484 defines the concepts involved in this project. A description of the chosen theoretical framework
485 and the change model selected to guide the desired intervention are included.

486 **Concept Analysis**

487 Major concepts in this project include FXS, SMA, newborn screening, Early Check,
488 information dissemination, and environmental scan. Concept analysis and definition is important
489 for understanding the components and their clear representation during the project
490 implementation. Concept definitions were developed after reviewing scientific publications,
491 journal articles, expert opinions, and internet resources for variations in perception and meaning
492 of each.

493 Many parties have done extensive research on *Fragile X syndrome* in the years since its
494 discovery. Some researchers have developed a complex list of symptoms associated with the
495 disorder, yet none were able to develop a reliable test for diagnosis or effective treatment. Per the
496 National Institutes of Health United States National Library of Medicine (2019), FXS is a
497 genetic condition that causes cognitive impairment, learning disabilities, and is accompanied by
498 several characteristic features such as a long face, macroorchidism, hypermobility of fingers,
499 large ears, and a prominent jaw. The Centers for Disease Control and Prevention (2018) defines
500 FXS similarly but provides statistics that males are more often and more severely affected than
501 females. Therefore, the concept of *Fragile X syndrome* was defined as an X-chromosome linked
502 genetic disorder, undetectable by traditional screening and examination, that is responsible for a
503 majority of single-gene related intellectual disabilities.

504 *Spinal muscular atrophy* is widely studied with many professional opinions and
505 definitions available for review. According to the Muscular Dystrophy Association (2018), *SMA*
506 is a genetic disease affecting the nerves in the spinal cord that control voluntary muscle
507 movement. For this project, the concept of *SMA* was defined as a genetic disorder, detectable
508 using the newborn blood sample, that affects the voluntary muscle control of a child and can
509 progress with varying degrees of severity. Depending on the identified type, *SMA* can
510 potentially lead to death by the age of two years.

511 *Newborn screening* is a nationwide process used to determine the presence of diseases
512 and disorders at birth before the presence of symptoms. Newborn screening can help to identify
513 conditions that will negatively affect the health and well-being of a child and can help to
514 diagnose, treat, and prevent early death and disability (Centers for Disease Control and
515 Prevention, 2019). The concept of *newborn screening* for this project was testing of a newborn
516 using a small blood sample obtained 24-48 hours after birth that evaluates for the presence of
517 conditions and disorders that will lead to disability or death if not detected prior to symptom
518 development.

519 *Early Check* is a relatively new program, but there has been a modicum of information
520 shared that allows for a complete understanding of the program and what it entails. Per RTI,
521 International (2019), *Early Check* is a research study implemented to screen babies for two rare
522 severe health conditions and is available to parents who sign up to have their babies tested. For
523 the purposes of this project, the concept of *Early Check* was a grant-funded program put in place
524 in North Carolina that offers free screening for FXS and *SMA* using the newborn screening
525 blood spot obtained from infants whose mothers who enrolled between 13 weeks of pregnancy
526 and up to four weeks postpartum.

527 *Information dissemination* has been broadly discussed, but little is known about the best
528 method and approach for sharing health information with the public on a grand scale. The term
529 information has been defined by Merriam-Webster (2019a) as “knowledge obtained from
530 investigation, study, or instruction.” Dissemination has been defined as the action of spreading
531 something widely (Merriam-Webster, 2019). For this project, the concept of *information*
532 *dissemination* was defined as the sharing of knowledge obtained from research with a broad
533 population, including OBGYN practitioners, midwives, clinic staff, and pregnant women and
534 their families.

535 *Environmental scan* is a term used to describe looking at the target environment and
536 collecting information that pertains to a particular subject. This information is then organized and
537 analyzed to assess areas of improvement and help to guide further planning. According to
538 Wilburn, Vanderpool, and Knight (2016), an environmental scan is a tool used by both
539 businesses and other organizations that helps to identify and assess challenges, strengths,
540 opportunities, and threats. For this project, *environmental scan* was defined as the process of
541 connecting with community partners that have contact with the target population of pregnant or
542 newly post-partum women to evaluate the current methods of information dissemination, the
543 efficiency of these methods, and opportunities to improve educational efforts as a whole.

544 **Theoretical Framework**

545 **Naming the theory.** The theoretical framework chosen to guide this project was Weick’s
546 organizational information theory (WOIT). This model describes the process involved in
547 organizing a set of interconnected communication processes that make sense of uncertainty and
548 help with problem-solving (Weick, 1969). This model, developed in 1969 by Weick, has been
549 utilized for the guidance of research and intervention development in the field of health

550 communication (Thompson, 2014). This theory has also been called Weick's model of
551 organizing and Weick's health communication theory. WOIT was created using concepts pulled
552 from three other theories: systems theory, information theory, and sociocultural evolution theory
553 (Thompson, 2014). Using these adopted concepts, WOIT encompasses the organization of
554 communication into interconnected processes that allow for the resolution of informational
555 uncertainty and the development of interventions to solve problems, adapt to new situations, and
556 enable growth (Kreps, 2009).

557 Concepts included in WOIT include *information environment*, *information equivocality*,
558 *organizational actors*, *organization participants*, and the *principle of requisite variety*. The
559 concept of the information environment is the interaction between the perception of a message
560 and the process of assigning a meaning to the information received (Kreps, 2009). Information
561 equivocality is the level of ambiguity, complexity, or obscurity in the message that affects the
562 ability to understand the information (Kreps, 2009). Organizational actors work to process
563 received information so that the prediction of future situations and responses can occur (Kreps,
564 2009). Organization participants attempt to maintain a balance between different levels of
565 uncertainty in the received information so the organization can begin to clearly understand the
566 information and respond appropriately (Kreps, 2009). The principle of requisite variety states
567 that the response to information must maintain the same level of complexity as that of the
568 message received (Kreps, 2009). If complex information is received, organizational actors must
569 interpret this information and respond to it in an equally complex manner to ensure adequate
570 understanding.

571 The two communication processes suggested by Weick to help cope with uncertainty in
572 information are *rules* and *cycles*. Rules are used to evaluate the level of uncertainty or to identify

573 the familiarity of a message (Kreps, 2009). After this, previously established standardized
574 responses from prior organizing processes are examined to determine if any apply to the message
575 received (Thompson, 2014). Rules are useful in response to simple messages with low levels of
576 complexity and ambiguity (Thompson, 2014). Cycles are small repeating message exchanges
577 used to dissect complex information so that ambiguity and complexity can be reduced, and
578 understandability can be enhanced (Kreps, 2009). Cycles allow for the receipt of a message, a
579 response to the information received, and an adjustment to be made before repeating the cycle to
580 continue reducing uncertainty. An example of a cycle is to utilize a consultation in the diagnosis
581 and treatment plan of a patient with a complex illness (Thompson, 2014).

582 These two communication processes are used in three communication phases: *enactment*,
583 *selection*, and *retention*. The enactment phase involves assigning meaning to information so that
584 the identification of appropriate rules and cycles can occur, and sense can be made of the current
585 issue (Kreps, 2009). The selection phase involves developing the best communication methods
586 for the most effective management of the specific issue (Kreps, 2009). The retention phase
587 occurs when information that is gathered is stored for use in new rule development and as a
588 database of experience to draw from in future health communication interactions (Kreps, 2009).
589 These phases work together to develop a *feedback loop*, a form of message system that can either
590 stimulate or stop the flow of information (Kreps, 2009). Positive feedback loops are used to
591 promote relevant information sharing to guide the development of health interventions that are
592 appropriate to the target population (Kreps, 2009). Negative feedback loops reduce or stop
593 information influx to reduce unnecessary communication interactions (Kreps, 2009).

594 **Application to practice change.** Weick's theory was chosen for this DNP project
595 because of its close alignment with health communication issues. This theory has been

596 considered an exemplary framework to help organizations understand varied and complex health
597 care situations and has helped to develop effective interventions (Kreps, 2009). Although this
598 theory can be used in a broad range of applications, it is particularly useful in dealing with health
599 communication strategies and intervention development.

600 Rules and cycles discussed in WOIT helped to drive the different phases of the DNP
601 project. Rules were represented by the patient education flyers that were disseminated to
602 practitioners, clinical staff, and patients. Rules also included the tool developed for use in the
603 environmental scan during the planning phase of the DNP project and the data collection tool
604 used during implementation. Cycles were represented by the overall project as it encompassed a
605 complex topic that required evaluation and clarification to reduce the ambiguity inherent in
606 successful health initiative communication efforts. Smaller cycles involved literature review
607 efforts, planning interventions, determining potential sites, securing sites, and developing a
608 schedule for implementation. Each of these activities was complex and required the development
609 of an idea, a response to the idea, and an adjustment to the response given.

610 The three phases of WOIT were also pivotal to the success of the DNP project.
611 Researching the background to make sense of the need for communication of the Early Check
612 initiative and conceiving of the project idea fulfilled the enactment phase. Meaning was assigned
613 to the impact that FXS and SMA have on children, and the importance of an intervention was
614 determined. The selection phase began with the development of the intervention plan based on
615 the current information and knowledge of the Early Check program and provider participation.
616 The retention phase occurred throughout the project but had the most impact after project
617 completion. Information gathered through the DNP project intervention and interpretation of

618 findings helped to simplify the complexity of the issue and helped form rules for use in future
619 research for this initiative and those to come.

620 **EBP Change Theory**

621 **Naming the change model.** The practice change model chosen for application in this
622 project was the Plan-Do-Study-Act, or PDSA, model. This model, a modification of Shewhart's
623 cycle, was created in 1986 by Deming (Deming, 1986). It has been widely used for research and
624 quality improvement across many different disciplines (Donnelly & Kirk, 2015). This model has
625 been utilized in quality improvement to focus activities on assessing, planning, enacting,
626 monitoring, evaluating, and reassessing the project goals and outcomes (Butts & Rich, 2018).
627 The PDSA model consists of four individual steps that all work together in a continuous cycle to
628 reach the optimal outcome of the intervention. The first step in the cycle is *Plan*. In this step, a
629 chosen process is studied, and an idea for improvement is developed (Butts & Rich, 2018). Data
630 that may help determine how to evaluate the process for evidence of improvement is decided on
631 in the *Plan* step (Butts & Rich, 2018). Once this step has been completed, the second step of the
632 PDSA cycle is put into place. The *Do* step involves the implementation of the plan (Donnelly &
633 Kirk, 2015). After the *Do* step, comes the third step, *Study*. In this portion of the PDSA cycle, the
634 results of the implementation phase are obtained and analyzed for the effectiveness of the
635 intervention (Butts & Rich, 2018). At this point, the need for modifications of the intervention
636 for optimal impact and goal attainment is determined (Butts & Rich, 2018). Finally, the fourth
637 step of the PDSA cycle, *Act*, is undertaken where the modified intervention is put into effect to
638 improve the process as planned at the beginning of the cycle (Butts & Rich, 2018). From this
639 point, a new cycle can begin to enact further changes in the process, thus continuing the PDSA

640 cycle. Performing process improvement in this manner helps to increase sustainability while
641 decreasing resistance to change in those involved (Donnelly & Kirk, 2015).

642 **Application to practice change.** The PDSA model has proven inherently useful in many
643 quality improvement projects and is a popular tool for change implementation. Utilization of the
644 PDSA model helped develop the implementation framework to promote the success of the
645 identified process improvement intervention. The PDSA model was an excellent tool to allow for
646 small changes in processes to be completed in short, rapid cycles making this model useful for
647 the limited time frame of this project.

648 The *Plan* portion of the model helped determine the population of focus and assist in
649 developing an intervention to promote awareness of the Early Check program. The *Plan* section
650 was used to identify OB/GYN providers and office staff as the target of the intervention. The
651 intervention, lunch and learns at OB/GYN offices, was developed and any barriers that may arise
652 in the implementation process were considered during this phase. The *Do* step occurred when the
653 lunch and learns were implemented, and awareness efforts were undertaken. During this phase,
654 OB/GYN practices that showed interest at the lunch and learn were provided with educational
655 information to present to pregnant women during the last four weeks of their pregnancy. The
656 *Study* step of the PDSA cycle allowed for evaluation of the lunch and learns as well as the
657 effectiveness of targeting OB/GYN providers and office staff. Effectiveness of the lunch and
658 learn activities to increase awareness of the Early Check program was scrutinized for effect and
659 provider participation. If the intervention was ineffective or less effective than desired,
660 modifications were suggested. In the *Act* step, the original intervention or modified intervention,
661 depending on effectiveness, was put into place to solidify the new, improved process. At this
662 point, the cycle was completed, or it was started again if further improvement efforts are desired.

663 Summary

664 In conclusion, concept analysis helped to understand the individual components of the
665 DNP project and assist in understanding how they interact. Concepts defined in this project
666 include FXS, SMA, Early Check, newborn screening, and information dissemination. Full
667 project-specific concept definitions can be found at the beginning of this chapter.

668 The theoretical framework chosen to serve as a guide for the DNP project was Weick's
669 organizational information theory. This theory was created using concepts from three other
670 theories: systems theory, information theory, and sociocultural evolution theory. The concepts of
671 this theory included rules and cycles used in three communication phases: enactment, selection,
672 and retention. The theoretical basis of this theory involves the presence of uncertainty, or
673 equivocality, in the information received and the responses necessary to reduce the ambiguous
674 and complex nature of information in order to respond to the information appropriately.
675 Aggregate information with a high level of equivocality requires complex responses often in the
676 form of cycles. Simple information with low levels of uncertainty may be responded to using
677 rules formed from previous information analysis. Feedback loops are used to either elicit needed
678 information or diminish unnecessary information as indicated. This theory applies to the DNP
679 project using the focus on reducing uncertainty in health care communication. The current level
680 of uncertainty in the population surrounding screening for FXS and SMA using the Early Check
681 program required a complex approach. Retention of the information learned from the DNP
682 project helped to form rules to apply to future research and quality improvement initiatives.

683 The change model chosen for the DNP project is the Plan-Do-Study-Act model. This
684 model is well known and used widely by many disciplines to promote change in small, quick
685 cycles for quality improvement. The four parts of this change model involve planning the

686 intervention, implementing the intervention, studying the results, and putting the intervention in
687 place permanently with any necessary changes. With the limited time frame of the DNP project,
688 this model allowed for assessment of current processes and timely alterations in the planning and
689 intervention stages along with a chance to evaluate the intervention's impact on reaching the
690 DNP project goal.

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709 **Chapter Four: Pre-implementation Plan**

710 The implementation of a successful project begins with the development of a
711 comprehensive plan. The plan was formulated after an extensive review of the literature and
712 collaboration with the researchers involved with the Early Check program. The theoretical basis
713 and change model of the plan include Weick's organizational information theory and Deming's
714 Plan-Do-Study-Act model. The following chapter discusses the pre-implementation plan, which
715 consists of the purpose of the project, various aspects of project management, the site-specific
716 requirements, and evaluation methods used during the implementation and post-implementation
717 phases of the project.

718 **Project Purpose**

719 The purpose of this project was to engage OB/GYN providers and their ancillary staff to
720 increase their knowledge and further the dissemination of information regarding the Early Check
721 initiative to pregnant or newly postpartum mothers. The overall goal of this project was to
722 increase parental awareness of the Early Check initiative and the opportunity for expanded
723 newborn screening that it presents. As OB/GYNs and their staff are in frequent contact with
724 pregnant women, their relationship was an untapped opportunity to disseminate health initiative
725 information. Encouraging the distribution of written information at prenatal appointments
726 between 36- and 40-weeks gestation had the potential to help to inform parents as well as
727 provide time to ask questions and seek clarification from the provider.

728 **Project Management**

729 **Organizational readiness for change.** Working with OB/GYN providers and their staff
730 required consideration of several aspects of care. An understanding of office workflow
731 requirements and time constraints for appointments was mandatory for the successful

732 implementation of information dissemination processes. Knowledge of office staff
733 responsibilities and their limitations was also essential. After reviewing the available literature, it
734 appeared that physicians are likely to be uninterested in health initiative dissemination due to
735 time and compensation constraints (Hayeems et al., 2009). While this made them less than ready
736 for change, other healthcare professionals, including nurse practitioners, midwives, and nurses,
737 were historically more amenable to sharing information regarding beneficial health initiatives
738 with their patients. A method of addressing physicians' lack of readiness for change involved
739 information sharing primarily by the distribution of written materials by ancillary staff at the start
740 of the appointment. This process allowed for the timely provision of information while avoiding
741 workflow and compensation concerns.

742 **Interprofessional collaboration.** Collaboration for this Early Check project involved
743 physicians, nurse practitioners, midwives, physician's assistants, registered nurses, and certified
744 medical assistants employed in OB/GYN offices in Forsyth County, NC. These individuals were
745 the target for education regarding the expanded newborn screening and the points of contact for
746 the dissemination of Early Check information to patients. The site champion, a representative of
747 RTI International, is a physician and research public health analyst who is deeply involved in the
748 Early Check initiative. Further collaboration took place with another research public health
749 analyst who serves as the Program Manager for the Early Check initiative. Representatives from
750 RTI International provided information regarding the Early Check program, helped to guide the
751 project timeline, and worked to further public awareness of the Early Check initiative. Much of
752 the groundwork for this project was attributed to the hard work of these representatives for Early
753 Check. The final participant in interprofessional collaboration was the faculty mentor from East

754 Carolina University. The mentor's role in collaboration was to engage and guide the student in
755 the development of a project worthy of doctoral rigor.

756 **Risk management assessment.** The risk associated with this project for the target
757 population of OB/GYNs, their ancillary staff, and the patients they are in contact with was
758 minimal. This project was solely intended for information dissemination, and no recruiting
759 efforts were involved. No contact between the project leader and potential participants occurred.
760 No protected health information was gathered, and no information was obtained on families that
761 may be at a higher risk for genetic anomalies.

762 There are several strengths and benefits associated with this project. Immediate benefits
763 of the project included the increase in provider knowledge, increased information dissemination
764 to the public, convenient testing without the need for another blood draw, and a potential
765 increase in newborns screened for FXS and SMA. Other benefits are more long term in nature.
766 Long-term benefits included timely interventions for affected infants, decreased family stress
767 with the knowledge of a definitive diagnosis, and increased family coping skills. With increased
768 screening and identification of children affected by FXS and SMA, individuals can be aware of
769 the need for testing in current and future generations born into the families.

770 Weaknesses associated with the project surrounded the willingness of the providers and
771 ancillary staff to disseminate Early Check health initiative information to their patients. Without
772 their buy-in, the use of this avenue of information dissemination was limited, thereby limiting the
773 public awareness of the Early Check initiative. Other weaknesses involved patient perceptions
774 and fear of participating in genetic testing and research. Many individuals are suspicious of
775 genetic testing and are hesitant to be a part of a research program.

776 Opportunities and threats were found in the providers' associated health systems. With a
777 willingness to participate, the health system provided a chance to adopt the dissemination of
778 Early Check information as a policy that encompasses many different facilities in other areas of
779 the state. The opposite is also true; health systems that were not willing to participate in the
780 project prevented engagement with providers and their ancillary staff in the project resulting in
781 limited parental awareness of the available screening. An equally concerning barrier involved
782 ethical considerations that providers and patients may have regarding genetic testing. Ethical
783 considerations when discussing genetic testing are the topic of much debate with few concrete
784 decisions available for reference.

785 **Organizational approval process.** Representatives from Early Check have implemented
786 strategies to disseminate information about the opportunity to expand newborn screening to the
787 public. These strategies were moderately effective, resulting in increased recruitment and
788 participation in the program. These strategies were state-wide but not necessarily for specific
789 geographical regions. After collaboration with Early Check representatives, Forsyth County was
790 chosen as a prime location as this area is a focal point for prenatal care for women in the
791 northwestern part of NC. Engaging OB/GYN providers and ancillary staff to develop a practice
792 model for information dissemination was accepted as potentially beneficial due to the increased
793 volume of exposure to pregnant and immediately postpartum women. Although previous efforts
794 to involve physicians met with obstacles, the inclusion of other providers and ancillary staff may
795 be useful for circumventing these barriers in the future. The RTI, International site champion
796 granted approval for this project.

797 **Information technology.** This project utilized Google Chrome for use with internet
798 searches to identify potential providers and OB/GYN offices for inclusion in the lunch and learn

799 invitations. Microsoft Excel© was utilized for the creation of the literature review matrix, the
800 project budget, and the environmental scan data collection tool. These Excel© spreadsheets can
801 be found in Appendices A, D, E, and F. No EHR was utilized for this project. WebEx
802 conferences were used to conduct meetings during the planning phase. BlueJeans, a
803 teleconferencing platform, was used to allow for video conferences with representatives from
804 RTI, International.

805 **Cost Analysis of Materials Needed for Project**

806 Flyers and other printed materials were created, printed, and provided by Early Check at
807 no cost to the student. Financial expenditure for food and refreshments was limited to \$100 per
808 lunch and learn event with a total of \$500 allotted for five events. PowerPoint presentations
809 regarding Early Check were developed with approximately 50 copies of each printed out by the
810 student for \$40 to distribute to providers and ancillary staff during the lunch and learn events.
811 Cost of fuel for travel between provider offices and trips to obtain refreshments approximated
812 \$40. See Appendix A for budgeting information.

813 **Plans for Institutional Review Board Approval**

814 Initial requirements for the approval process involved completing the Collaborative
815 Institutional Training Initiative (CITI) training modules for both the East Carolina University's
816 (ECU) IRB and the University of North Carolina's (UNC) IRB that oversees the Early Check
817 initiative. Completion certificates were submitted to both organizations and can be found in
818 Appendices B and C. Increasing provider and ancillary staffs' knowledge about Early Check and
819 implementing a practice model for information dissemination had the potential to impact
820 research participants. Therefore, approval by an IRB was necessary. To meet the necessary IRB

821 requirements, the student was added to the UNC IRB currently in place with the reliance
822 agreement between UNC and ECU.

823 **Site-Specific Requirements**

824 Working with RTI International carried a few site-specific requirements for the
825 completion of the DNP project. Several project planning meetings were held via online meeting
826 platforms to discuss project expectations and develop a timeline for progression. Further
827 meetings were conducted by phone and online conferences to ensure adequate student
828 preparation for speaking to providers and their ancillary staff about the Early Check initiative.
829 Finally, an environmental scan was proposed to evaluate the climate of the student's proposed
830 area. These data were provided to the representatives of Early Check for their use in future
831 research efforts.

832 **Plan for Project Evaluation**

833 **Demographics.** Demographic information collected in the student developed data
834 collection tool included name, years of practice, role, and location. See Appendices D and E for
835 the data collection tool utilized. Demographic variables will be reported individually with the use
836 of histograms and pie charts as appropriate to provide visual reference points. Years of practice
837 are reported as means with standard deviations and ranges. Clinician's roles were indicated using
838 percentages for each category. Location participation was reported using percentages.

839 **Outcome measurement.** This DNP project involved two independent outcomes. The
840 first outcome measure calculated the number of OB/GYN offices in Forsyth County, NC that
841 participated in a lunch and learn activity to hear about Early Check. The second outcome
842 measure was the number of OB/GYN offices that expressed interest in forming a practice model

843 for information dissemination about expanded newborn screening to pregnant and newly
844 postpartum women.

845 *Evaluation tool.* An Excel© spreadsheet was created to log data during the completion of
846 the environmental scan. Information obtained during the completion of the environmental scan
847 included contacts, affiliations, current education methods, willingness to educate women, and the
848 autonomy the contact felt they had in choosing what education to provide. This information was
849 used to determine the offices and providers to contact during implementation. An Excel©
850 spreadsheet was utilized to log the number of providers or offices contacted for potential
851 participation in the lunch and learn activity. Successful contacts were recorded with a list of next
852 steps taken. Specific contact information was included for future interaction in those that showed
853 interest in participation with the lunch and learn activity. Information regarding office size and
854 variety of staff available was gathered for event planning. Practices interested in participating in
855 the development of a practice model for information dissemination regarding expanded newborn
856 screening were identified and logged with site contact information and the name of the site
857 representative. See Appendix F for the evaluation tool used in this DNP project.

858 *Data analysis.* Data analysis was completed by comparing the total number of OB/GYN
859 providers/practices contacted with the number of OB/GYN providers/practices participating in
860 the lunch and learn activity. Further analysis was completed by comparing the number of
861 OB/GYN providers/practices that participated in the lunch and learn activities with the number
862 of providers/practices that showed interest in developing a practice model for information
863 dissemination about expanded newborn screening. There were no specific comparative
864 benchmarks for this DNP project at the time of its implementation.

865 **Data management.** Data for the environmental scan and provider participation logs were
866 collected in two separate Excel© spreadsheets. The information for the environmental scan
867 included provider name, provider credentials, years of practice, affiliations, location, methods of
868 educating women, preferred timing of education, willingness to participate in education about
869 Early Check, and perception of autonomy in their role. Both willingness to participate in
870 education about Early Check and the perception of autonomy were rated using a five-point Likert
871 scale. The information included in the provider participation spreadsheet included provider
872 name, years of practice, affiliations, receptiveness to education, and interest in forming an office
873 practice model for the distribution of Early Check information to patients. A separate Excel©
874 spreadsheet was created for provider offices that chose to create a practice model and included
875 information regarding the preferred educational method and the timing of education provision to
876 pregnant women. Information was maintained throughout project completion in both paper and
877 digital formats. Backup copies of the completed spreadsheets were maintained on an encrypted
878 flash drive dedicated solely to the DNP project. Data access privileges were granted to the
879 student, ECU faculty mentor, and RTI International representatives. No patient protected
880 information or private health information was collected for use in this DNP project.

881 **Summary**

882 The DNP project was implemented in Forsyth County, NC, and involved the completion
883 of an environmental scan prior to the dissemination of expanded newborn screening information
884 to providers and their ancillary staff. A risk analysis was performed with several immediate and
885 long-term benefits and risks identified. Organizational readiness for change was estimated to be
886 poor in terms of physicians, but midlevel providers and ancillary office staff were potentially
887 more approachable. Providers and their ancillary staff were approached with education regarding

888 the Early Check initiative via a lunch and learn format. Collaboration occurred with interested
889 provider offices to develop a practice model for sharing Early Check education with patients.

890 Project outcome evaluation was completed by calculating the number of providers
891 contacted with the number that showed interest in lunch and learn participation. Further outcome
892 evaluation involved comparing the number of providers that participated in lunch and learn
893 activities with those that were interested in practice model development. Data were collected
894 using Excel© spreadsheets to reflect providers, roles, years of practice, affiliations, and
895 locations. Data were also collected regarding provider willingness to participate in educating
896 patients, their perceived autonomy in practice, and their preferences for providing education.
897 Collected information was stored securely with access granted to the key individuals that had a
898 vested interest in the project.

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911 **Chapter Five: Implementation Process**

912 Implementation of the DNP project occurred in the Fall of 2019. Collaboration with
913 researchers at RTI International, faculty at East Carolina University, and key individuals in the
914 community was integral to the smooth implementation of the proposed strategies. This chapter
915 will discuss the details of the implementation process and help to define the setting, participants,
916 and processes involved.

917 **Setting**

918 Information dissemination surrounding the expanded newborn screening offered by the
919 Early Check program was directed at the OB/GYN provider offices of Forsyth County, NC.
920 Overall, the offices targeted were for-profit agencies caring for both gynecological and
921 obstetrical patients. Many of these offices have affiliations with nearby hospitals and healthcare
922 systems that provide care to patients within Forsyth and the surrounding counties. Obstetrical
923 patients cared for in these offices are provided labor and delivery care at the two nearby hospitals
924 unless an alternate delivery plan is desired by the patient. As obstetric care providers see such a
925 large population, increasing provider awareness of the Early Check program will contribute to
926 the potential spread of information to a larger number of patients and families.

927 **Participants**

928 An environmental scan completed during the planning phase of the DNP project helped to
929 create a database of OB/GYN offices located in Forsyth County. OB/GYN offices were
930 contacted regardless of affiliation with larger health systems. Organizations included were
931 advertised to provide prenatal and postpartum care to women. Individuals that were included as
932 participants included practice administrators, office managers, physicians, physician assistants,
933 nurse practitioners, midwives, registered nurses, and certified medical assistants. Staff in contact

934 with patients on a daily basis or those with involvement in the administrative decisions of care at
935 the office were also included as participants. Staff involved with scheduling, billing, or other
936 administrative processes that did not include direct patient interaction were excluded from
937 participation.

938 **Recruitment**

939 Recruitment efforts consisted of contacting all OB/GYN offices in the Forsyth County
940 borders via telephone. As the primary person responsible for the day to day operations, contacts
941 within each office included the office manager or practice administrator. Each office manager or
942 practice administrator was contacted to discuss the project, obtain permission to visit the office,
943 and schedule a lunch and learn with the target participants. If unable to speak directly with the
944 desired contact, a voicemail message was left with a brief description of the purpose of the call in
945 addition to phone and email contact information for the student.

946 Practice administrators and office managers that answered directly or returned phone calls
947 to the student received an explanation of the Early Check program, the DNP project, and the
948 student's goals. Those that expressed interest in a lunch and learn were included in the
949 participants for the project, and a suitable date was scheduled. Those that declined the
950 opportunity to participate in a lunch and learn with the student were thanked for their time and
951 removed from the participants' list. Practices were removed from the list of participants after two
952 unreturned voice mails and two unanswered emails if available.

953 This convenience sample was obtained through contact with key individuals in each office
954 and depended largely on the individual's willingness to participate in the DNP project's
955 proposed intervention. Potential barriers to participation were time constraints, feelings of
956 limited authority to decide what education to present to providers, and a poor understanding of

957 the Early Check program and DNP project purpose. Limitations may include a lack of time or
958 interest on the part of the provider and ancillary staff. Potential participant concerns involved
959 expectations to remember and share additional information in an already overwhelming system
960 of care.

961 **Implementation Process**

962 The first step in the implementation process was to formulate a comprehensive list of
963 OB/GYN providers operating in Forsyth County, NC. After using internet resources and visiting
964 office webpages to determine their patient population and services, a list was compiled of all
965 offices meeting the criteria for inclusion in the project. Due to the limited number of OB/GYN
966 offices in the area, all offices meeting the inclusion criteria were contacted for participation in
967 the DNP project.

968 Once identified, all offices were contacted via telephone with the request to speak to the
969 practice administrator or office manager. Phone conversations that ensued included information
970 on the Early Check program, the DNP project, and the details of participation in a lunch and
971 learn activity. Questions were answered as needed. Finally, interest in participation was assessed,
972 and if amenable, a date for the lunch and learn was scheduled. For individuals that did not
973 answer the call, a voicemail was left with a brief explanation of the purpose of the call and the
974 student's email and phone contact information. If no response to the initial call, a follow-up call
975 was made within a week with a second voicemail left if necessary. Offices with no response
976 from either phone call were emailed if the correct email address was obtained. No response after
977 the voicemails and email was considered a declination of participation, and the office was
978 removed from the list of potential participants.

979 **Lunch and Learn Activity.** Offices that chose to participate in the lunch and learn
980 activities were recorded on an Excel spreadsheet. Lunch and learns were completed as scheduled
981 with interested offices. After completion of the lunch and learn presentation, providers and
982 ancillary staff questions were answered. Educational resources printed and provided by RTI
983 International regarding Early Check were provided to each staff member for further personal
984 investigation. A brief PowerPoint© was provided by RTI International, edited and printed by the
985 student, and distributed to staff for a clearer understanding of the progress of Early Check thus
986 far.

987 **Office Dissemination Process.** Each office was evaluated for interest in developing a
988 process of Early Check education provision to pregnant patients between 36 weeks and 40 weeks
989 gestation. If interested, the student worked with key individuals in the office to develop a
990 streamlined process to minimize staff effort and maximize patient education.

991 **Plan Variation**

992 The initial implementation plan included targeting OB/GYN practices in Forsyth County,
993 NC. This geographical location provided a limited number of practices to contact and even fewer
994 that responded to contact efforts. Large health systems interested in participation had practices
995 outside of the Forsyth County area that desired to host presentations. After a discussion with
996 representatives of RTI International and the faculty mentor, the decision was made to broaden
997 outreach to include Surry, Wilkes, Davie, Davidson, Guilford, Rowan, and Alamance Counties
998 in an effort to increase the potential impact of the project. Broadening the outreach allowed for
999 practices affiliated with multiple health systems to be included in the participants' list.

1000 The method of presentation was also altered from the original plan. The original intent to
1001 hold lunch and learn activities was abandoned due to practice and health system policies

1002 prohibiting such events. Instead, presentations were completed during lunch hours, staff
1003 meetings, and monthly practice conferences. Presentations were limited to 10-15 minutes and
1004 conducted verbally with printed PowerPoint presentations provided to the participants. Printed
1005 examples of flyers were available as a visual example of the information provided to patients.

1006 The dissemination process for participating offices also underwent changes. Initially, the
1007 plan for disseminating information to patients involved developing a process to share flyers with
1008 patients who were 36- to 40-weeks gestation. Early in the implementation process, practices
1009 were found to have preferred timing of flyer dissemination determined by current office
1010 processes. With this finding, suggestions were made on preferred timing and methods, but each
1011 office was allowed to determine the optimal time to share flyers with patients and the process
1012 used to do so. Practice administrators conferenced with providers and clinical staff in the practice
1013 then notified the student of the process decided upon.

1014 **Summary**

1015 Implementation of this DNP project involved contacting all OB/GYN offices in Forsyth
1016 County, NC, for participation in information dissemination about the Early Check program. Due
1017 to the limited number of OB/GYN practices in the target area, the outreach was broadened to
1018 include practices in Surry, Wilkes, Davie, Davidson, Rowan, Iredell, Guilford, and Alamance
1019 Counties. Offices were contacted by phone and email. The idea of in-person visits was
1020 considered but ultimately determined unproductive as practice administrator availability without
1021 notice was questionable. In-person visits were also made impractical because of the larger
1022 geographical area encompassed in the broadened outreach.

1023 Offices interested in participation were scheduled for a brief presentation at the time most
1024 convenient for the practice. Offices that were not interested were thanked for their consideration

1025 and removed from the list of potential participants. Verbal presentations were completed as
1026 scheduled with targeted information given to providers and their ancillary staff on Early Check
1027 and the goals of the DNP project. Each participating office was evaluated for willingness to
1028 develop an information dissemination process regarding Early Check to pregnant or newly
1029 postpartum women. Offices interested in developing a process for information sharing preferred
1030 to determine the best timing and method depending on their practice workflow. Once the office
1031 determined the desired process, the student was notified for reporting purposes.

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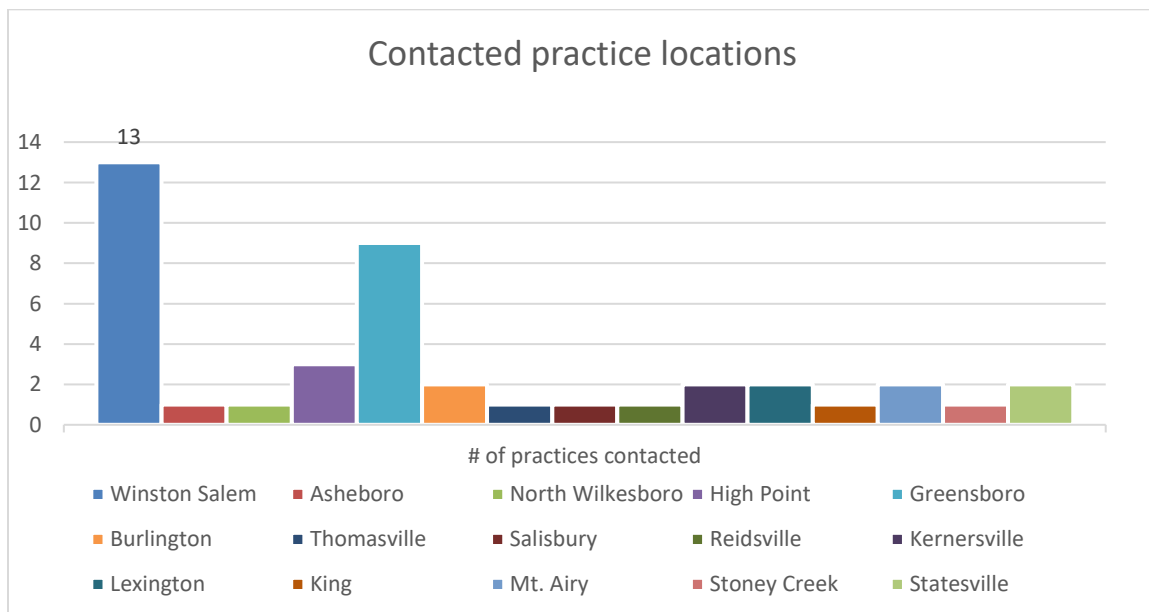
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1048 **Chapter Six: Evaluation of the Practice Change Initiative**

1049 This DNP project was undertaken to increase OB/GYN provider and ancillary staff
 1050 awareness of the Early Check program. Increasing knowledge of new health initiatives among
 1051 medical providers is vital when promoting practice change for a population. This chapter will
 1052 discuss participant demographics, project outcomes, and summarize the impact of the
 1053 intervention.

1054 **Participant Demographics**

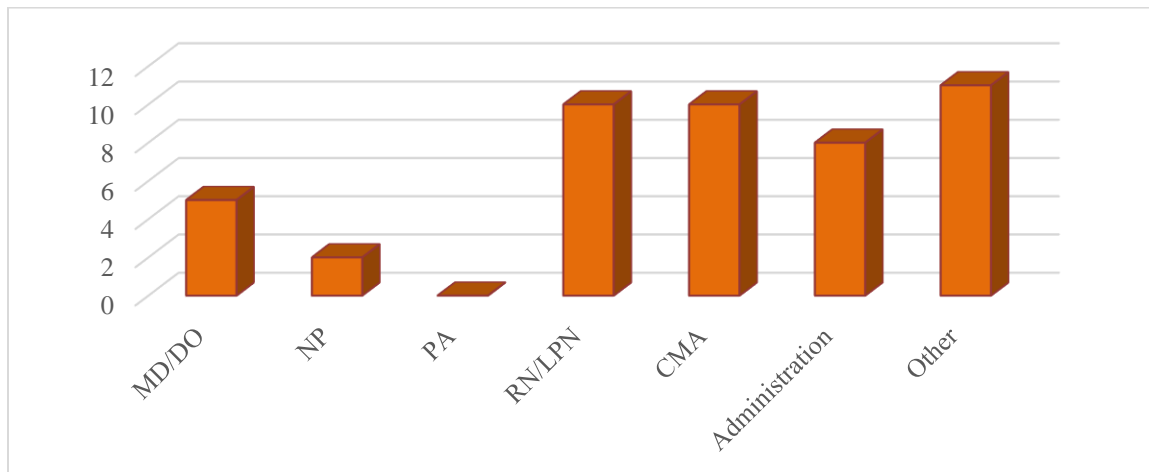
1055 Outreach to OB/GYN offices was undertaken beginning in late August and continued
 1056 through early December. Offices contacted were geographically located in 15 cities throughout
 1057 nine counties of NC. Counties included in the outreach area included Alamance, Forsyth,
 1058 Guilford, Davidson, Davie, Iredell, Stokes, Surry, and Wilkes. See Figure 1 for a synopsis of
 1059 practice locations. Overall, there were 42 offices contacted with responses received from 10.
 1060 Responsive practices were located in North Wilkesboro, Winston Salem, Asheboro, and High
 1061 Point.



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 1063 *Figure 1. Practices Contacted by Location. This figure shows the number of locations*

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1065 contacted in each geographical area.

1066 Practices that chose to participate in the project were provided with a brief, in-person
1067 education session. Attendants of education sessions included MDs, NPs, RNs, LPNs, CMAs,
1068 administrative staff, and “other.” The “other” category included ultrasound techs, phlebotomists,
1069 and clinical coordinators. See Figure 2 for a cumulative identification of education session
1070 participants’ roles. The number of years in role varied widely with several outliers that skewed
1071 statistical measures. The mean years in role was 10.95 years with a standard deviation of 11.32
1072 years. Years in role also had a range of 41 and a mode of 1 year.



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1074 *Figure 2.* Roles of Education Session Attendees. This figure explains the breakdown of
1075 education session attendees by job role.

1076 **Intended Outcomes**

1077 This DNP project’s purpose was to increase the awareness of OB/GYN providers and
1078 ancillary staff regarding the expanded newborn screening opportunity available to North
1079 Carolina residents via the Early Check program. Associated goals of the project included
1080 increasing provider engagement, patient knowledge of the program, and the number of infants

1081 screened for FXS and SMA. Intended outcomes are discussed below in terms of short-,
1082 intermediate-, and long-term expectations.

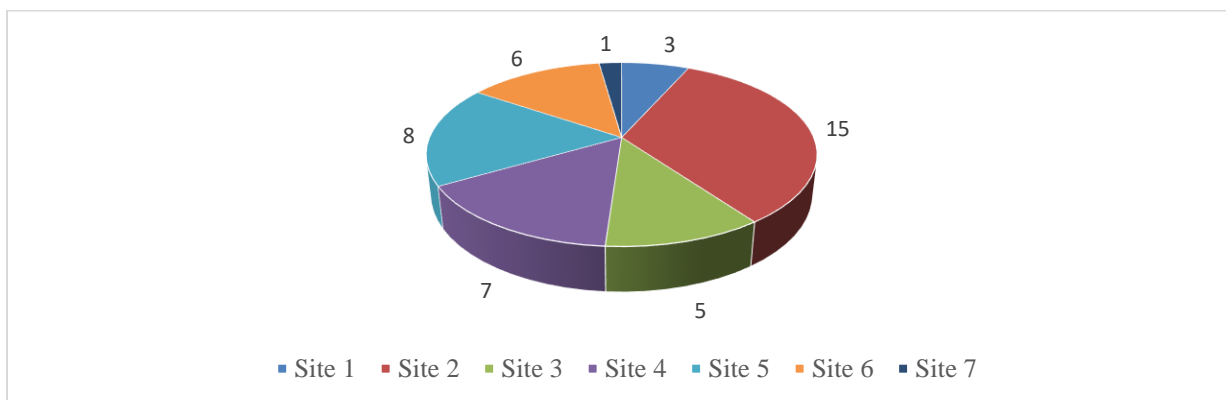
1083 Intended short-term outcomes were to increase OB/GYN providers' and ancillary staff's
1084 knowledge regarding the opportunity for free expanded newborn screening in North Carolina.
1085 Despite repeated outreach via phone and email, the vast majority of practices contacted did not
1086 respond. For practices that did respond, practice managers or clinic administrators were the
1087 interested parties when discussing education sessions. Increasing provider engagement was also
1088 an intended short-term outcome of the project. Providers were involved in the education sessions
1089 in only two practices and were largely unavailable in the remaining five due to scheduling or
1090 disinterest. Ancillary staff were more responsive to outreach and education efforts, which
1091 resulted in more uptake of education sessions and increased participation in flyer dissemination.
1092 This increase in flyer dissemination helped to reach the final short-term intended outcome of
1093 increased patient knowledge of the Early Check program.

1094 Intended intermediate outcomes included increasing the number of mothers participating
1095 in Early Check and, thereby, the number of infants screened for FXS and SMA. Increasing
1096 identification of infants affected by these two conditions can trigger referrals for services that can
1097 help to implement early intervention while also providing a more accurate measure of the
1098 prevalence of each condition. Another intermediate goal was enhancing provider partnership and
1099 engagement for future health initiatives. Through the development of relationships with practices
1100 during this project implementation period, it is possible that further collaboration may occur in
1101 months to come on both Early Check and new population health programs.

1102 Intended long-term outcomes include the development of best practice recommendations
1103 for sharing health initiative information with the population. While this project outreach had a

1104 low number of participants, the potential impact of the intervention is significant. Engaging
 1105 providers and their ancillary staff in sharing health initiatives with their patients shows promise
 1106 to reach a large number of individuals with minimal effort or expenditure. The final long-term
 1107 outcome involves the addition of screening for FXS and SMA to the state newborn screening
 1108 panel using the evidence gained by the Early Check program. By achieving this goal, all
 1109 newborns in our state can benefit from early screening, identification, and intervention.

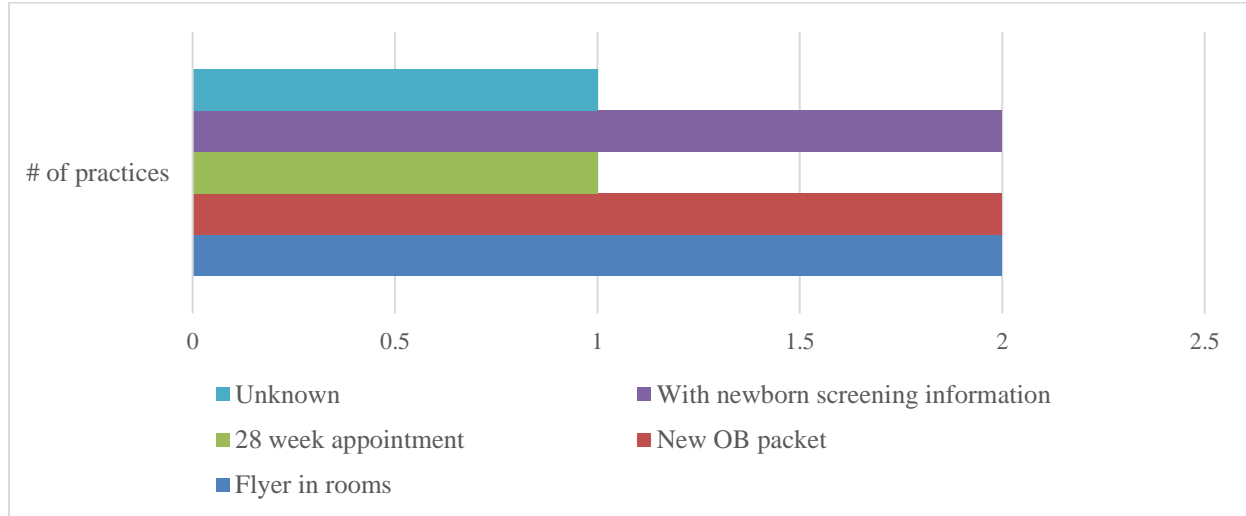
1110 **Findings.** Of the 10 responses received during the outreach, seven practices participated
 1111 in an education session. Education session attendance varied per location, with the least number
 1112 of participants being one and the most being 15. See Figure 3 for attendance by location. All
 1113 seven practices that participated in the education session agreed to disseminate flyers to their
 1114 patients. Methods of dissemination varied per office and included the distribution of flyers in
 1115 new OB packets or at 28-week appointments, posting flyers in each patient room, and sharing
 1116 flyers along with the newborn/metabolic screening process. See Figure 4. One practice was
 1117 already aware of the Early Check program and declined to host an education session. This
 1118 practice did agree to distribute flyers to their patients, but information was unavailable on
 1119 methods of dissemination due to poor follow up responses from the practice administrator.



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1121 *Figure 3.* Education Session Participation by Location. This figure shows the number of
 1122 people who attended education sessions in each location.

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1125 *Figure 4. Methods of Dissemination by Practices.* This figure shows the different
 1126 methods of flyer dissemination and how many practices chose to use each method.

1127 The potential impact of the intervention is difficult to calculate as each practice was
 1128 allowed to choose their dissemination method, and specific practice population numbers were
 1129 not available. Practices that decided to include the flyer in the New OB packet will potentially
 1130 reach every woman presenting with a new pregnancy. Unfortunately, inclusion in the New OB
 1131 packet increases the likelihood of the flyer being overlooked due to the wide variety of
 1132 information included. The two practices that chose to post the flyer in patient exam rooms have
 1133 the potential to reach even more patients, including non-pregnant women that may have pregnant
 1134 family members. This method promoted repeated exposure from early in pregnancy to full-term,
 1135 which could encourage questions and increase the uptake of the program. These practices have
 1136 extra flyers on hand for women that show interest in participation or would like more
 1137 information. The one practice that chose to disseminate the flyer at the 28-week appointment will
 1138 reach most pregnant women at the practice with the exclusion of those with known diabetes that

1139 do not need to undergo the glucose tolerance testing that is part of traditional prenatal care.
1140 Finally, the two hospital delivery units that participated will be presenting the information in
1141 conjunction with delivery and the hospital stay. The potential reach of this method of
1142 dissemination includes all women who deliver at the hospitals, which totals greater than 7,000
1143 deliveries per year. Collaboration with the Director of Women's and Children's services at one
1144 hospital opened the door for flyer dissemination at all the other OB/GYN facilities associated
1145 with the health system. However, currently, only three of the 10 facilities are participating.

1146 **Summary**

1147 Collaboration with OB/GYN practices in Forsyth and surrounding counties of NC was
1148 somewhat labor-intensive but met with moderate success in provider education and engagement
1149 in disseminating Early Check education to the population. While outreach encompassed 42
1150 practices, less than one-fifth responded. Of the practices that did participate in education sessions
1151 or had received previous education, 100% of them chose to share information with their patients.
1152 This level of participation alone has the potential to reach more than 7,000 pregnant and newly
1153 postpartum women each year.

1154 Given the uptake of flyer dissemination among practices that chose to participate, it could
1155 be extrapolated that the challenge of practice participation in the dissemination of Early Check
1156 information is practice engagement instead of limited interest in helping increase awareness of a
1157 new health initiative. Potential limiters of this project's intervention include the timing of the
1158 intervention, limited availability of the practice administrator, and practice policies that prevent
1159 the addition of new patient education. The outcomes of this DNP project prove that providers
1160 and their ancillary staff can successfully share information about new health initiatives with the

1161 population, but further inquiry must be made to establish best practice for connecting with
1162 practices and promoting provider engagement.

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1184 **Chapter Seven: Implications for Nursing Practice**

1185 According to the American Association of Colleges of Nursing (AACN), all Doctor of
1186 Nursing Practice programs across the nation must integrate eight essential curricular elements
1187 and competencies (AACN, 2006). These essentials help to ensure the highest level of leadership
1188 and scientific inquiry and are considered to be the foundation of Doctor of Nursing Practice
1189 degrees (AACN, 2006). This chapter outlines the eight essentials and how they each applied to
1190 the planning and implementation phases of the DNP project.

1191 **Practice Implications**

1192 **Essential I: Scientific underpinnings for practice.** Weick's organizational information
1193 theory was utilized as the scientific basis for the dissemination of information regarding the
1194 Early Check program in North Carolina. Utilizing Weick's theory, information was presented to
1195 OB/GYN practices in several counties of North Carolina to document the effectiveness of these
1196 practitioners in disseminating information regarding new health initiatives in North Carolina.
1197 Although there has been no single method of information dissemination determined most
1198 effective, OB/GYN practices show promise in reaching a maximum number of the population
1199 targeted in the Early Check initiative.

1200 Weick's theory involves sharing information in short, understandable cycles to reduce
1201 uncertainty and aid in the reduction of the complexity of messages (Kreps, 2009). Information
1202 was presented to OB/GYN practices using short messages of concise, easy to apply information
1203 to reduce uncertainty and aid in the understanding by those receiving the message. Cycles were
1204 completed, and alterations in processes were made using feedback from each education session.
1205 Communication with OB/GYN practices was continued after the initial education session to
1206 maximize the retention of information and evaluate processes set for sharing flyers with patients.

1207 Weick's theory is lesser-known and not utilized as often as others but has proven to be a
1208 valuable approach to sharing information. The value in this theory lies in sharing information in
1209 a way that maximizes understanding and retention while reducing uncertainty and discomfort
1210 associated with poor comprehension of messages. This theory, in conjunction with the benefit of
1211 using medical professionals who are already well-educated on the importance of expanding
1212 newborn screening, proved to be of great benefit in reaching the pregnant and newly post-partum
1213 population in the participating areas.

1214 **Essential II: Organization and systems leadership for quality improvement and**
1215 **systems thinking.** There is little evidence available in the literature to support the benefit of
1216 targeting OB/GYN providers to disseminate information to pregnant and newly post-partum
1217 patients. Despite this, the high level of exposure to the patient population made this a prime
1218 target to evaluate the effectiveness of information dissemination. Hayeems et al. (2009) state that
1219 lack of time and reimbursement are reasons for poor physician participation in sharing new
1220 information with patients. With that in mind, practices were provided education sessions to enlist
1221 the aid of other medical professionals and create a process that requires minimal time
1222 expenditure. Core competencies of Essential II include critical thinking and effective
1223 communication of practice knowledge using both written and verbal methods to improve quality.
1224 These competencies were demonstrated by the provision of flyers, PowerPoint printouts, and
1225 verbal presentations to practices based on the on-site analysis of practice needs and interest in
1226 participation.

1227 The development of strategies to allow for patient education about expanded newborn
1228 screening in participating practices was performed based on practice preferences. Determining
1229 the appropriate point of contact with each practice required much inquiry and both formal and

1230 informal communication approaches. Several key individuals were able to provide contact
1231 information and help facilitate communication with practices. Collaboration with practice
1232 managers appeared to be most effective as they were more aware of the value of sharing the
1233 Early Check information with patients and proved to be the most effective contact to schedule
1234 education sessions.

1235 **Essential III: Clinical scholarship and analytical methods for EBP.** Evaluation of the
1236 available literature on newborn screening and health initiative information dissemination was
1237 completed with the determination to test the effectiveness of OB/GYN practices in educating
1238 patients about the Early Check program. The PDSA cycle was utilized to analyze each step in the
1239 implementation of the project, and each modification was documented. Changes after each cycle
1240 were evaluated for effectiveness in future cycles.

1241 While the implementation of the project was targeted toward OB/GYN providers and
1242 their effects on increasing patient knowledge, it was found that others in the practice such as
1243 clinical coordinators and practice managers have more buy-in and influence on practice
1244 participation. Future initiative rollouts should consider this finding when approaching practices
1245 for participation in disseminating information to the population. In the future, research aimed at
1246 provider participation facilitators and barriers could help to better understand how to fully
1247 engage practices as a whole.

1248 **Essential IV: Information systems/technology and patient care technology for the**
1249 **improvement and transformation of healthcare.** A literature review was completed using
1250 online databases maintained by East Carolina University's Laupus Library. The review was
1251 completed of pertinent subjects, including newborn screening, Early Check, Fragile X syndrome,

1252 spinal muscular atrophy, and information dissemination. Information found in the literature
1253 review helped to guide the development of the DNP project.

1254 Further technology utilized included Microsoft Excel© spreadsheets to track practice
1255 information and participation. The spreadsheet included practice names, locations, administrator
1256 names, number of participants in the education session, and interest in participation in
1257 information dissemination to patients. Microsoft Outlook© was utilized for email
1258 communications. Internet search engines were used to compile a list of OB/GYN practices in the
1259 Forsyth County area as well as in surrounding counties. Cellular phone service was used for
1260 telephonic encounters with practice administrators and navigation assistance when visiting sites
1261 on the day of presentation.

1262 **Essential V: Healthcare policy for advocacy in healthcare.** As previously discussed,
1263 newborn screening is determined by each state individually despite having a national
1264 Recommended Uniform Screening Panel (RUSP) (Kemper, 2019). To be added to the RUSP, a
1265 condition must meet several different criteria, including cost-effective testing and the potential
1266 for effective treatment of the disease. On the state level, the process is even more challenging to
1267 navigate as there must be a state review process that will evaluate for benefits, harms, resources,
1268 capacity, impact on healthcare systems, and stakeholder input (Botkin et al., 2015). Early Check
1269 is working toward proving the benefit of screening for FXS and SMA while exhibiting the low
1270 cost and resource use. Increasing the awareness of the population increases the possibility that
1271 parents can take part in this opportunity and help to gather evidence to support the addition of
1272 these conditions to the NC newborn screening panel.

1273 Currently, there is no specific policy regarding the dissemination of health initiative
1274 information to the population. While many studies have been done on communicating with the

1275 public regarding new initiatives, there have been no clear answers regarding what works best.
1276 The success of interventions to share information depends primarily on the targeted population
1277 and location. This DNP project is helping to establish best practice methods for reaching a
1278 significant percentage of the population.

1279 **Essential VI: Interprofessional collaboration for improving patient and population**
1280 **health outcomes.** Interprofessional collaboration is an essential part of providing high-quality
1281 healthcare to the population at all levels. Increasing the public's awareness of an opportunity,
1282 such as expanded newborn screening, requires the involvement of a number of different
1283 professionals both in and out of healthcare. In this project, collaboration with OB/GYN practices
1284 was effective and resulted in the development of information dissemination processes at all
1285 seven of the offices that agreed to presentations and one office that had prior knowledge of the
1286 program. Practices that participated were affiliated with two large medical centers and were very
1287 receptive to hosting educational sessions about the project. Most often, the individuals
1288 expressing interest were the practice managers, but other healthcare professionals were able to
1289 attend the sessions, such as certified medical assistants, clinical coordinators, and registered
1290 nurses. Providers attended individual sessions at two out of the seven practices that participated.

1291 Interprofessional practice was utilized outside of the education sessions to ensure the
1292 success of the project. Collaboration with researchers at Early Check, upper-level administrators
1293 at local health systems, and front-desk staff was integral to making appropriate contacts and
1294 being able to carry out the planned intervention. With continued outreach and expanded target
1295 populations, the potential for interprofessional collaboration will expand exponentially.

1296 **Essential VII: Clinical prevention and population health for improving the nation's**
1297 **health.** Prevention of disease and improvement of population health are cornerstone components

1298 of Healthy People 2020 (Office of Disease Prevention and Health Promotion, 2019). To meet
1299 these ideals, it is necessary to identify health disparities and clinical conditions as early as
1300 possible. Early identification of FXS and SMA can provide many benefits such as early
1301 intervention, prevention of needless diagnostic testing, and prevention of sequelae associated
1302 with each condition. While each condition affects only a relatively small number of patients, the
1303 healthcare expenditures are conversely very high, requiring unmeasurable amounts to pay for the
1304 various aspects of patient care. While there is currently no cure for either condition, there are
1305 interventions available that have allowed the affected individuals to lead healthier lives with
1306 fewer limitations.

1307 Interacting with practice managers and ancillary staff at OB/GYN practices to
1308 disseminate information about the Early Check program and its availability to the public is an
1309 important step in broadening the reach of expanded newborn screening and early identification.
1310 With the varied social and geographical reach that OB/GYNs have, there is the potential for
1311 widespread dissemination of information on health initiatives. The strategy of collaboration with
1312 OB/GYN practices was successful and has helped increase the awareness of expanded newborn
1313 screening in the target area's population. Future health initiatives could benefit from targeting
1314 providers and practices for their participation in disseminating information.

1315 **Essential VIII: Advanced nursing practice.** Knowledge and experience of an advanced
1316 practice nurse are essential to help improve population health. The use of these skills can help to
1317 identify and address disparities while encouraging health promotion and improving quality of
1318 life. Through the use of knowledge and experience, potential targets were analyzed for the
1319 significance of impact when disseminating health initiative information. After completing the
1320 critical analysis, the decision to target OB/GYNs was made. This decision proved to be

1321 beneficial and helped to disseminate information to the public as predicted. Future outreach of
1322 health initiatives should consider collaborating with healthcare providers to further their
1323 information dissemination reach.

1324 As outreach continues, it is vital to maintain and broaden interprofessional relationships.
1325 Advanced practice nurses should make every effort to collaborate with a wide variety of
1326 professionals. While working with OB/GYNs has proved successful in this DNP project, there is
1327 no proof that this strategy is the most successful. Further study is needed to determine the best
1328 strategy for health initiative information dissemination.

1329 **Summary**

1330 The eight essentials utilized in Doctor of Nursing Practice programs allow for the
1331 development of leadership, skills, and core competencies to ensure proper preparation for
1332 practice. These essentials are applied and interpreted differently depending on the focus of the
1333 program or specialty. The DNP project encompassed each of the eight essentials, as described
1334 above. Of particular importance to this project were scientific underpinnings for practice, clinical
1335 scholarship, and interprofessional collaboration.

1336 Scientific underpinnings were necessary to give the project a scientific basis and guide the
1337 development and implementation of the intervention. Clinical scholarship was exhibited with
1338 literature review and identification of gaps in knowledge and processes. Utilizing
1339 interprofessional collaboration made this project possible as many individuals came together to
1340 embrace expanded newborn screening information dissemination. Collaborating with OB/GYN
1341 practices shows promise as an effective strategy for disseminating information, but more effort is
1342 needed to reach the rural population without access to adequate healthcare providers. Continued

1343 research is necessary to determine the most effective recruitment and information dissemination
1344 strategies.

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1366 **Chapter Eight: Final Conclusions**

1367 Population health initiatives have the potential to positively affect the health and wellness
1368 of our communities, but the information must be shared on a broad scale for this to happen. In
1369 this DNP project, information regarding expanded newborn screening opportunities was shared
1370 with the hope that OB/GYN practices would help inform their patient population about the Early
1371 Check program. This chapter will discuss the significance of project findings along with
1372 strengths, weaknesses, benefits, and limitations identified. Also included in this chapter are
1373 practice recommendations for future project planning efforts.

1374 **Significance of Findings**

1375 Collaboration with OB/GYN practices in disseminating Early Check information was
1376 moderately successful. Despite the low number of participating practices, the impact of the
1377 intervention potentially increased exposure to Early Check information by thousands of women
1378 per year. On further evaluation, however, this project led to several significant findings that may
1379 be beneficial in future dissemination efforts for population health initiatives.

1380 This project encompassed a broad geographical area covering nine counties and reaching
1381 out to several large health systems in North Carolina. Although the majority of practices did not
1382 participate in education sessions, the ones who did are disseminating flyers to patients in five
1383 counties. In addition, the two hospitals that are disseminating information about Early Check
1384 serve patients from numerous surrounding counties that this project may not have reached. In
1385 conjunction with the broad coverage area, there are many different ways that information about
1386 Early Check may be spread to the community. Formally, patients have received flyers or been
1387 exposed to flyers and posters while at their appointment. Also, patients have been exposed to
1388 Early Check information after giving birth when presented with newborn screening information.

1389 Informally, word of mouth from family members, friends, and acquaintances who may have seen
1390 flyers or posters help to spread the word about expanded newborn screening. Some others may
1391 gravitate toward participation in the Early Check program as they follow the example set by
1392 friends, family, coworkers, and public figures. With this in mind, the potential for reaching
1393 pregnant and newly postpartum women in North Carolina from this intervention is more
1394 significant than is realizable with the data gathered during the short time this project was
1395 implemented.

1396 Interprofessional collaboration with OB/GYN practices allowed for the creation of a
1397 partnership. As providers to a large population of patients, these individuals have the ready
1398 access needed to increase community knowledge in a short time period. Creating a trusting
1399 relationship with these providers may prove useful as future health initiatives are developed and
1400 shared with the population. To maximize the benefit of this relationship, the development of best
1401 practice methods for provider engagement is needed. In the majority of participating practices,
1402 providers were not participants in Early Check education sessions or the decision to distribute
1403 flyers to their patients. With this knowledge, determining the person responsible for the decision
1404 to share health initiative information may prove more efficient and productive when promoting
1405 new programs.

1406 Disseminating information is a time-consuming process that requires patience, diligence,
1407 and creative thinking. Outreach to OB/GYN practices was completed via phone and email.
1408 Difficulties with obtaining contact information for the practice administrators hindered the
1409 outreach process. Voicemails are often not the best points of contact as they provide limited
1410 information and are frequently deleted without listening fully. Phone calls directly to the practice
1411 are regularly screened by front desk staff who may not convey the intent of the message

1412 accurately. The success of phone calls depends greatly on timing and daily schedules of practice
1413 administrators. In retrospect, in-person visits to OB/GYN practices in the target area could have
1414 resulted in increased successful contact with practice administrators and increased the likelihood
1415 of participation.

1416 Sharing of information with practices also depends on practice schedules and time
1417 considerations. In-person education sessions were successful in conveying adequate information
1418 and allowing for clarification questions and further inquiry beyond basic knowledge. The process
1419 of scheduling and completion of education sessions was driven by Wieck's organizational
1420 information theory (Kreps, 2009). Information was relayed in small sections and evaluated for
1421 understanding to prevent confusion and poor comprehension. This approach was successful in
1422 ensuring that education session attendees were fully aware of the Early Check program and the
1423 benefits of expanded newborn screening. Seeking practice input on the education provided
1424 allowed for changes in the presentation approach. Allowing practices to determine their specific
1425 methods of dissemination increased the likelihood of participation in Early Check flyer
1426 distribution.

1427 **Project Strengths and Weaknesses**

1428 Strengths of this project included confirmation of OB/GYN practices as legitimate means
1429 to disseminate population health initiatives to the pregnant population. Despite the low number
1430 of responses from outreach efforts, practices that did respond and participate in the dissemination
1431 of Early Check information have the capability to reach thousands of patients every year.

1432 Another strength of this project was the development of partnerships with OB/GYN practices
1433 throughout two major health systems that may provide future collaboration opportunities as more

1434 health initiatives are developed. Finally, the minimal costs of this project allowed for a broader
1435 outreach area and inclusion of more practices in education sessions than initially intended.

1436 Weaknesses of this project revolved around poor access to practice administrator contact
1437 information and poor response rates from practices. This weakness played an essential role in
1438 limiting the uptake of the intervention and the potential impact of the project. A further weakness
1439 involved the inability to engage more providers in the education sessions. Without the necessary
1440 information, providers will be limited in their ability to answer patients' questions about the
1441 Early Check program when asked. The final weakness identified in this project was the
1442 cumbersome time spent in attempts to formulate a list of practices and repeated outreach efforts.

1443 **Project Limitations**

1444 The inability to successfully contact practice administrators was a severe limitation to this
1445 project, requiring a broadening of the target area to engage enough practices in participation for
1446 an honest evaluation of the intervention. Once the target area was broadened, this eliminated the
1447 potential option for in-person visits to practices to speak face-to-face with practice
1448 administrators. With the widened coverage area, time was not available to visit all practices, so
1449 face-to-face efforts were excluded, thereby limiting the tools to establish contact. Some practices
1450 shared a practice administrator with several locations. In this case, the inability to successfully
1451 contact the practice administrator excluded multiple practices from participation in the project.
1452 Finally, most company policies prohibited the provision of lunches for lunch and learn activities.
1453 Without this limitation, some practices may have been more interested in education session
1454 participation.

1455 **Project Benefits**

1456 The most obvious benefit of this project is the potential for the sharing of information with
1457 thousands of women throughout Western North Carolina regarding Early Check. Allowing
1458 offices to determine their method of dissemination has allowed for patients of all ages in certain
1459 practices to be exposed to Early Check information at each appointment. This increases the
1460 potential for word of mouth to qualifying pregnant women that may not have exposure at their
1461 clinic to Early Check flyers.

1462 Another significant benefit of this project involved providing education to pregnant or
1463 newly postpartum women to enhance their knowledge of expanded newborn screening. Ensuring
1464 a complete understanding of the Early Check initiative, who it is available to, and what to expect
1465 when opting in is essential. Sharing flyers that direct women to educational resources about the
1466 program can help to ensure that they get accurate information designed to be understandable at
1467 most reading levels. With this education, women can make informed decisions with a full
1468 understanding of the resources available for infants that screen positive. The hope is that with a
1469 better understanding of the program, more women will choose to participate in the Early Check
1470 program and more infants will be screened for FXS and SMA.

1471 Although developers of Early Check planned to approach medical providers later in their
1472 project, they started dissemination using letters, postcards, and social media outreach. At the
1473 beginning of the Early Check study, providers throughout the state were provided with a brief
1474 message about the program but were not approached to share information with their patients.
1475 Although suspected to be an effective method of health initiative dissemination, this DNP
1476 project's findings provided proof that collaboration with providers and clinical practices is a
1477 successful approach to increasing population awareness. Early Check representatives can use
1478 these findings to tailor clinical involvement efforts to the most influential individuals, such as

1479 practice managers or office administrators. In addition to practice participation, this project made
1480 it possible to develop collaborative partnerships with providers, administrators, and key
1481 individuals in the medical community throughout Forsyth County that have far-reaching
1482 connections.

1483 **Practice Recommendations**

1484 Outcomes of this DNP project provided valuable information for future initiative
1485 dissemination efforts. Collaboration with physicians and clinical practices was proven to help
1486 increase awareness of population health initiatives and should be of utmost importance. This
1487 project's findings can be applied to other health initiatives with modification of targeted practice
1488 types depending on the population in question.

1489 For future outreach, aiming initial communications toward practice managers or office
1490 administrators can increase the likelihood of participation and uptake of education. Further
1491 evaluation of barriers to provider participation in education sessions is necessary. Knowing what
1492 would motivate providers to increase participation in such activities could help determine
1493 alternate approaches to educate clinicians successfully. Other modifications involve the methods
1494 of outreach utilized for initial contact with practices. While telephone and email contact were not
1495 wholly unsuccessful, in-person visits to practices hold the potential to help with the identification
1496 and engagement of key individuals that determine practice participation efforts.

1497 Continued efforts on behalf of Early Check researchers to spread the word about expanded
1498 newborn screening and engage as many pregnant women as possible in program participation is
1499 imperative. With recent legislative changes, the long process of submitting a disease for
1500 consideration for addition to the newborn screening panel has drastically shortened. Gathering
1501 information on the prevalence and impact of FXS and SMA in our state can provide the evidence

1502 needed to support legislation changes and the addition of these conditions to the state's newborn
1503 screening panel. Success in this could ensure that every child born in North Carolina has the
1504 potential to receive screening and early identification of these two conditions.

1505 **Final Summary**

1506 This DNP project targeted OB/GYN practices to increase provider and clinical staff
1507 knowledge about the Early Check program, and hopefully raise patient awareness about
1508 expanded newborn screening in North Carolina. The findings of this DNP project can be useful
1509 in developing future health initiative dissemination efforts. Interprofessional collaboration with
1510 OB/GYN practices was a successful intervention for sharing information pertaining to pregnant
1511 patients, but providers are not as engaged as office administration and clinical support staff.
1512 Phone outreach can be used to create initial connections with practices but is often unreliable due
1513 to unanswered calls and voice mails. Email can be helpful in contacting key individuals in
1514 practices, but obtaining email addresses is often difficult, and email messages may not receive a
1515 reply. In-person visits to practices were not evaluated in this intervention but may provide more
1516 reliable contact with practices for outreach efforts and engagement in health initiative education.

1517 While this project met with some success in engaging practices in education sessions and
1518 flyer distribution, there is still more work to be done to ensure that information about Early
1519 Check reaches inhabitants throughout all areas of the state. Dissemination of health initiative
1520 education requires creativity, innovation, and perseverance to ensure the population receives the
1521 information necessary to promote overall health. Dissemination efforts can take many forms and
1522 must be tailored to the target population with consideration for location and education levels.
1523 The use of continued interprofessional collaboration combined with prior research and quality

1524 improvement efforts, regardless of outcomes, can help to formulate best practices in promoting
1525 health initiative engagement in the population.

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Appendix A

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Project Budget

Project budget									
Item	Projected cost	Actual cost	Difference	Notes					
Early Check promotional materials									
- Flyers	\$0.00	\$0.00	\$0.00	Provided by Early Check representatives at no cost					
- Videos	\$0.00	\$0.00	\$0.00						
- Printed materials	\$0.00	\$0.00	\$0.00						
Lunch and learn activities									
-Five events at \$100 each	\$500	pending	pending	Variable depending on uptake of participation					
Patient education sheets									
- Created by student	\$0.00	\$0.00	\$0.00	For use in patient packets in practices that participate					
-Printing materials (paper/ink)	\$40.00	\$40.00	\$0.00						
Travel costs									
- Fuel costs x 1 tank of gas	\$40.00	\$40.00	\$0.00	For travel to OB/GYN offices					
Totals									
	\$580.00	pending	pending	Pending final tally of costs					

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Appendix B

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Human research CITI certificate, East Carolina University

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Appendix C

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Human research CITI certificate, University of North Carolina at Chapel Hill



Completion Date 11-Mar-2019
Expiration Date 08-Mar-2029
Record ID 30894740

This is to certify that:

Joy Jessup

Has completed the following CITI Program course:

Human Research	(Curriculum Group)
Group 2 Social and Behavioral Research:	(Course Learner Group)
1 - Basic Course	(Stage)

Under requirements set by:

University of North Carolina at Chapel Hill

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w3d48bfa3-76c5-4efe-984f-30319c6fdace-30894740

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Appendix D

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Environmental scan tool page 1

Name	Role	Years of Practice	Location	Affiliations (health systems, universities, etc)	Methods of Educating Women	Timing of Educating Prenatally or Post-Partially	Willingness to Educate Women (5-point Likert-type scale)?	How much autonomy do you have in selecting the information and education you share with women and families (5-point Likert-type scale)?	Notes:

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Appendix E

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Environmental scan tool page 2

# of Prenatal Clinics	# of Women Served	Are there prenatal classes available?	If so, when and where?	# of Places that allow pamphlets	# of Places that have a television in waiting rooms	Availability to speak directly to prenatal groups?

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Appendix F

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Project Evaluation Tool

Site	# of participants	MD/DO	NP	PA	RN/LPN	CMA	Administration	Other
Site 1	3	0	0	0	2	0	1	0
Site 2	15	0	0	0	1	4	1	9
Site 3	5	3	1	0	0	0	1	0
Site 4	7	1	1	0	0	3	1	1
Site 5	8	0	0	0	4	3	1	0
Site 6	6	1	0	0	3	0	1	1
Site 7	1	0	0	0	0	0	1	0
Site 8	1	0	0	0	0	0	1	0
Total	46	5	2	0	10	10	8	11

Participant #	Years in role	Participant #	Years in role
1	35	24	2
2	4	25	2
3	1	26	3
4	31	27	20
5	13	28	10
6	5	29	17
7	4	30	1
8	11	31	1
9	10	32	1
10	1	33	3.5
11	8	34	7.5
12	4	35	1
13	2	36	25
14	4	37	14
15	38	38	10
16	15	39	20
17	12	40	4
18	42	41	Unknown
19	6.5	42	Unknown
20	35	43	Unknown
21	11	44	Unknown
22	1.5	45	Unknown
23	2	46	Unknown

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