Improving Primary Care Awareness and Screening of Adults with Familial Hypercholesterolemia Through an Online Provider Educational Program

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Abstract

BACKGROUND: Familial Hypercholesterolemia (FH) is the most common genetic condition resulting in cardiovascular disease, a leading cause of death in the United States. FH is estimated to affect 1 in 250 individuals with elevated lipid levels present from birth. An estimated 90% of individuals with FH remain undiagnosed. **OBJECTIVES:** The purpose of this quality improvement project was to increase provider awareness and promote screening for FH among adults ages 20 years and older by: 1) educating providers about FH; 2) evaluating lipid screening practices on admission and every five years; 3) evaluating treatment status for clients exceeding the LDL-C 190 mg/dL cut-point; and 4) evaluating project impact on lipid screening practice. **METHODS:** A pretest and posttest quality improvement project design was used with retrospective chart review, assessment of providers' FH knowledge and lipid screening practices documenting the proportion of patients screened for FH. **RESULTS:** Outcome measures of FH knowledge were reported using descriptive statistics. An independent samples *t*-test showed no statistically significant change in screening practices pre/post-intervention ($p = 0.976$), with a mean interval of 2.09 years between initial and subsequent testing. Regression analysis yielded a medium correlation effect between age and lipid testing intervals, with the interval between testing decreasing by .028 years for every one-year increase in age. The proportion of clinic patients exceeding the expected population estimate for FH was significant ($p < .001$). Return of clinical impact survey data did not occur. **CONCLUSIONS:** EMR data identified undiagnosed patients in the clinic population at risk for FH. Knowledge surveys identified themes for further provider FH education.

Keywords: familial hypercholesterolemia, primary care, lipid screening, heart disease

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Heart disease continues to be the leading cause of death in the United States, contributing $219 billion to annual direct and indirect healthcare costs since 2014 (Office of Disease Prevention and Health Promotion [ODPHP], 2020a). A log-linear relationship between low-density lipoprotein cholesterol (LDL-C) levels and cardiovascular disease (CVD) has been consistently reported in the literature (Vijan, 2020). Multiple professional guidelines recommend lipid screening every five years to address this highly modifiable cardiovascular risk factor (ODPHP, 2020a). CVD affects approximately 40% of American adults and is associated with a high-fat diet and atherogenic lifestyle choices (ODPHP, 2020b). However, for an estimated 1 in 250 individuals, severely elevated lipid levels are present from birth due to genetic factors referred to as familial hypercholesterolemia (FH). According to the Centers for Disease Control and Disease Prevention (CDC, 2014), FH is designated as a Tier 1 genomic disorder because it is one of the most common inherited disorders, results in premature morbidity and mortality, is treatable, yet often goes unidentified. Heterozygous FH individuals generally have plasma cholesterol levels above the 95th percentile and are identified in populations worldwide (De Castro-Orós et al., 2010).

FH is an inborn, autosomal dominant disorder of lipid metabolism and confers a higher risk of premature CVD, potentially shortening life by 15-20 years (Nordestgaard et al., 2013). Diagnosis may be accomplished through clinical assessment using established criteria and readily available lipid profile testing, frequently ordered by primary care providers (Bell et al., 2014; Goldberg et al., 2011). An estimated 90% of individuals affected by FH remain undiagnosed or under-treated, and therefore are unaware they have a life-threatening condition

(Brett et al., 2018). A practice gap for screening, diagnosis, and treatment of FH currently exists. The purpose of this quality improvement project is to increase provider awareness and promote lipid screening in the primary care setting, with a focus on identifying FH for adults 20 years and older. Although there is a lack of consensus over how early to screen for dyslipidemia (Vijan, 2020), the ACC/AHA 2018 cholesterol treatment guideline addresses adults 20 years and older. Study of lipid screening practices for children-adolescents ages 0-19 was outside the scope of this project and were not included in the Healthy People 2020 guidelines. Examining providers' lipid screening behavior for adults 20 years and older was selected because recommendations for this sub-population is supported by both the ACC/AHA cholesterol treatment guidelines (Grundy et al., 2019) and the Healthy People 2020 lipid screening guidelines (ODPHP, 2020a).

Problem Identification and Significance

Direct medical costs and lost productivity in the U.S. related to CVD are projected to increase 83% from $656 billion in 2015 to $1.2 trillion by 2035 (Mozaffarian et al., 2015). National FH screening programs are recognized as a public health priority in more than 60 countries worldwide (Vallejo-Vaj et al., 2018). The U.S. does not currently have a national FH screening program; however, practice guidelines to improve cholesterol management are available (Grundy et al., 2019).

Barriers to FH screening include: the absence of a national health service, lack of public and provider awareness regarding FH, gaps in documentation of family history impeding use of diagnostic criteria, multiple proprietary EMRs prohibiting standardization of search protocols, the absence of EMR based clinical decision support tools and a lack of consensus around when and for which individuals should screening be done (Hasnie et al., 2018; Wändell et al., 2018; Zimmerman et al., 2019; Vijan, 2020). Added impetus for this project was contributed by

prevalence data from the FH Foundation's "Heat Map®" (The FH Foundation, n.d.), estimating 580-1,159 of people living in the project site area are likely affected by FH. Since 90% of individuals with FH are estimated to be undiagnosed, this suggested 522-1,043 of the population within this project site area have possible FH and are yet to be screened, accurately diagnosed, and offered treatment.

Purpose and Goals

The purpose of this quality improvement project was to increase provider awareness of FH and to promote FH screening among adults ages 20 years and older by the following:

- increase providers' knowledge about FH through education
- evaluate a change in lipid screening and FH diagnoses for treatment-naïve patients with LDL-C levels ≥190 mg/dL at time of admission, and every five years
- evaluate the initiation of treatment orders entered for diagnoses of hyperlipidemia for treatment naïve clients identified with LDL-C levels ≥190mg/dL
- evaluate the educational intervention's impact on clinical practice

The screening parameters for this project is consistent with the current Healthy People 2020 lipid screening recommendations (ODPHP, 2020).

Literature Synthesis

Education as Intervention

Most journal articles on the topic of FH and how to facilitate screening in primary care, originated outside the U.S. Zimmerman et al. (2018) conducted a study involving 175 physicians in Minnesota to identify perceived barriers to FH screening. A majority of respondents (56%) indicated that having access to an algorithm to guide lipid disorders management helped identify

FH. The American Heart Association/American College of Cardiology cholesterol management guideline (Grundy et al., 2019), is an algorithm-style flow chart designed to promote use in the clinical setting by providers (see Appendix C). Likewise, Elkins and Fruh (2019) addressed the need to increase FH knowledge among nurse practitioners through a continuing education article, supporting their recommendation that Nurse Practitioners should diagnose patients with FH and begin treatment as early as possible. Barriers to FH awareness and screening can be summarized to include a complex set of structural, organizational, professional, patient-related, and attitudinal issues. Indeed, evidence suggests increased provider education is an effective strategy to address the practice gap in FH screening (Wändell et al., 2018; Withycomb et al., 2015).

Lipid Screening Practice

Multiple studies exploring methods for detecting individuals with FH in a primary care population have concluded that EMR database search protocols, including analysis of diagnosis codes to identify practice patterns, facilitated the identification of those who may have FH (Banda et al., 2018; Lan et al., 2019; Vickery et al., 2017; Weng et al., 2018). The simplified FH screening protocol described by Green et al. (2016) recommended that clients who met or exceeded the cut-point of LDL-C $\geq$190 mg/dL undergo further evaluation to rule out secondary causes or to confirm a diagnosis of FH. The work by Green et al. (2016) provided a practical, evidence-based approach upon which to develop the methodology for pre/post-intervention data extraction for this DNP project.

Theoretical Framework

Providers' adoption of evidence-based practice guidelines is critical to improving the quality of care (Institute of Medicine [IOM], 2011). A theoretical model that effectively supports the integration and dissemination of new information, such as practice guidelines and technology

changes, is comparable to Rogers' (2003) diffusion of innovation theory (DOI). Application of Rogers' model can be useful in clinical settings with the introduction of technology-based interventions, such as EMR database searches to guide practice. Kaminski (2011a) pointed out that Rogers' model yields the benefits of integrating Lewin's classic social change "unfreeze-change-freeze" model (Kaminski, 2011b). Subtle social dynamics elements were added with the application of DOI concepts (see Appendix D). The introduction of screening for FH as a new clinical topic, was identified as precipitating change or "unfreezing." Providers' perception of simplicity, relative advantage, compatibility with existing workflow, and "trialability" (or ease of trying out the change) were expected to impact engagement (Rogers, 2003). The "re-freezing" or adoption/non-adoption phase was anticipated to occur when the diffusion process attained complete "saturation" and stabilization throughout the organization (Kaminski, 2011a).

Methods

Design

A pre/posttest quality improvement project design with retrospective chart review assessed provider knowledge and screening practices documenting the proportion of patients screened for FH. Post-intervention clinical impact surveys were then sent out to providers by email. IRB review and approvals were obtained before the start of the project.

Setting

This DNP quality improvement project was conducted at an independent primary care practice with two locations in Southwest Washington, serving a patient population of approximately 3,500 patients. The EMR system includes data from both sites from 2013 forward.

Participants

Participants for this project include the following provider staff who rotate to both sites: one Nurse Practitioner, a Physician Assistant, and three Physicians. The focus population included a patient base of approximately 3,500 clients aged 20 years and older. Total clinic census in 2019 and 2020, as reflected by active EMR cases, was 3,291 and 3,869 respectively. The county population has nearly equal numbers of males and females, with 77% identifying as white.

Procedure

The FH knowledge pretest-posttest surveys were sent by email to all five clinic site providers through a link to Survey Monkey, a commercially available online survey tool. The email content included a continuing education article and quiz by Elkins and Fruh (2019). The authors granted permission for the use of the article and posttest for this project. A content map was developed for the educational intervention (see Appendix A), and a project description was emailed with the article to the clinic providers. Laminated copies of the cholesterol management guideline algorithms (Grundy et al., 2019) were provided as part of the educational program (see Appendix C). Periodic emails with brief project updates, additional resources, and the opportunity to ask questions or share comments with the student investigator were sent to providers to promote project engagement and the adoption of new practice information.

According to the literature, the adoption of Clinical Practice Guidelines (CPGs) also requires attention to delivery mode beyond the simple provision of written documents (IOM, 2011). Didactic or passive transmission of information, such as reading or other self-directed learning methods, are not reported to be successful unless paired with some level of interaction by the learner with the material. Based on this information regarding CPG adoption, the integration of case studies with didactic material was planned to help foster learner engagement

with presentation within the context of a group setting (Bluestone et al., 2013). Onsite interactive case discussions were not able to be carried out due to COVID-19 site visit restrictions.

Data Collection

Data collection for the first project goal, to measure providers' knowledge about FH through education, was measured by pre/post-education surveys**.** An 18-item pretest (see Appendix B) was administered in September 2020 to all participants through email using a link to Survey Monkey and completed during the first week of a one-month long intervention period. One week was allocated for respondents to read the article and return the same quiz as a posttest. All responses were collected anonymously. Participants had the option not to participate by simply not completing the survey. The posttest quiz had a separate link to Survey Monkey and was open for a one-week post review of the instructional content and provided a compiled summary of responses.

Clinic population demographic data was limited to the categories of age and gender. EMR database searches were accessed to address evaluation of changes in lipid screening and diagnosis entry as indicators of potential post-intervention changes in practice. A spreadsheet data collection tool was created in Microsoft Excel to summarize de-identified extracted data for later analysis.

A retrospective chart review was conducted by EMR database searches to compare proportions of lipid tests recorded pre/post-education from October 1-November 30, 2019, and October 1-November 30, 2020. The sample was limited to 250 randomly selected patients ages $\geq$ 20 years seen during each two-month collection period. This data set included intervals for initial and follow-up lipid testing interval; identification of cases meeting or exceeding the cut-point of 190mg/dL as possible FH; diagnosis entry; and presence of treatment orders for any FH

diagnoses. See Appendix F, the EMR Data Extraction Flow Chart, for an overview of the data collection process.

Since the EMR database did not include family history information required for application of more specific FH diagnostic criteria, such as the MedPed or Dutch Lipid Clinic Network FH classification systems (Zamora et al., 2017), FH was defined as those individuals meeting or exceeding the treatment näive190 mg/dL LDL-C cut point. Evaluation to assess adherence to the Healthy People 2020 five-year screening interval (ODPHD, 2020b) was accomplished with the pre-intervention group. The time-limited data collection period precluded the collection of five-year interval testing data for the post-intervention group with the idea of establishing a benchmark for longitudinal data gathering should the practice elect to do so. Evaluation of ICD-10 diagnostic codes (World Health Organization [WHO], 2020), and treatment orders for patients identified with LDL-C levels suggestive of FH as well as non-specific hyperlipidemia, described the burden of diagnosed lipid disorders compared to those with normal lipid levels.

Evaluation of the fourth goal, intended to measure providers' perceived impact of the education aimed at increasing FH awareness and screening, were to be measured by responses to the post-project evaluation of impact on practice survey. Responses to Likert-scale questions were structured to reflect the degree to which providers reported a post-intervention change in practice (see Appendix E).

Ethical Considerations

This quality improvement study presented no identifiable risks to patients; no adverse events were anticipated to occur. Contact with providers occurred through the practice's internal email and did not involve contact with patients. Findings are reported using only de-identified

data in the aggregate. Patient and provider confidentiality were continuously maintained by strict data management techniques. De-identified data extraction reports for patient and provider data were saved in password-protected cloud-based, HIPAA-secure EMR storage, accessed through the practice's internal network. De-identified data for computational purposes were stored in Microsoft Excel on the student's private, two-step authenticated, password-protected computer. All hard copy printouts contained only de-identified data, maintained in a secure location, and were shredded when no longer used. After the project concludes, the secured data will be retained by Gonzaga University for three years to be kept in a secure location and subsequently destroyed.

Findings

Outcome analysis for measures of FH knowledge by the 18-item questionnaire (see Appendix B) was limited to the description of topics requiring further education since two out of the four respondents for the pretest were different from those who completed the pretest due to staffing changes and scheduling factors. Responses were pooled since there was no way to statistically compare the pretest and posttest groups given the difference in membership. However, it was possible to identify topics for further education as seven out of 18 questions had 75% or fewer correct responses based on a total of 8 respondents (see Table 1). In the case of question number 1, only 1 of 8 total attempts was correct; the pooled score of 1/8 or 12.5% was rounded to 13%.

Table 1

Pooled Scores of <75% Correct by Question for Pre/posttest Responses

Number	Question	Average Score

1	The LDL-C level in patients with homozygous FH is most likely to be: ***Four times that of the general population level***	13%
14	Which non-statin therapy inhibits the absorption of cholesterol and has very few drug interactions? ***Ezetimibe***	13%
3	All of the following clinical presentations are suggestive of FH except: ***Corneal arcus before age 60***	50%
10	Why are cardiovascular risk assessment tools not valid in patients with FH? ***Tools underestimate the length of time patients are exposed to high levels of cholesterol***	50%
6	Cholesterol screening for patients with a family history of elevated cholesterol should begin at what age? ***2 years***	63%
13	Which statement best describes the adverse reactions of statins? ***Approximately 1% of patients experience ALT and AST levels that are more than three times the upper limit of normal***	63%
12	When using statins to treat FH: ***Due to reliance on LDLR, goal reduction with high-intensity classified drugs may be 25%***	75%

Retrospective EMR database record searches explored lipid testing for a two-month period one year prior to the post-intervention data collection period. The first part of the second goal was to identify if the provider confirmed a lipid test was present on admission or was obtained within three months post-admission. The remaining part of the goal was to identify if patients were re-screened at the five-year mark to meet Healthy People 2020 lipid screening guidelines.

Collecting data to examine adherence to an every five-year screening guideline was possible using pre-2015 admissions data from the pre-intervention cohort. These data would provide a desirable benchmark going forward; however, the project goal did not reflect that it would not be possible to perform a longitudinal comparison with the post-intervention group during the time permitted. Alternatively, it was possible to examine pre-intervention lipid screening intervals from admission to the first/initial lipid screening. An independent samples t-test, effect size analysis, and regression analysis were utilized to address the project goals with a modified focus of measuring lipid screening intervals from admission to follow-up. Analysis of the mean number of years between lipid screenings for the pre-and post-intervention groups is displayed in Table 2. Although the 2-tailed independent samples t-test showed no significant difference in mean years in lipid screening from time of admission to the practice and initial screening, between the pre-post intervention groups (see Table 3), repeating this test over time may provide helpful quality improvement feedback against this initial benchmark.

Table 2

Comparison of Initial and Follow-up Lipid Testing Intervals

Condition	N	Mean	Standard Deviation	Standard Error Mean
Oct-Nov 2019 Cohort	143	2.09	1.389	.116
Oct-Nov 2020 Cohort	117	2.09	1.568	.145

Note. The mean intervals for lipid screening between the time of admission to the practice and the initial lipid test are in fact the same; the difference is not statistically significant

With respect to analysis by independent samples t-test, it should be noted that the samples from the 2019 and 2020 cohorts respectively, were treated as independent since the individuals were from the same sample but observations were not paired. Testing was therefore done for two different independent samples, (2019 and 2020 cohorts), under different conditions.

Table 3

Independent Samples t-test for Pre/postintervention Lipid Screening Intervals

	F	*p*	t	df	Significance 2-tailed	Mean Difference
Equal variances assumed	1.782	.183	.030	258	.976	.005
Equal variances not assumed			.029	233.958	.977	.005

Note. A 2-tailed independent samples t-test showed no significant difference between cohorts

The results of a bivariate regression model with age predicting intervals between lipid tests are presented in tables 4 and 5.

Table 4

Regression Analysis Lipid Testing by Age

R Predictor: Age	R^2 (% Variance)	Adjusted R^2	Standard Error of the Estimate	p-value
.323	.104	.101	1.393	$p < .001$

R is essentially the correlation coefficient when there are only two variables and can be described as approaching a medium effect since the obtained R^2 of 0.1 is less than the suggested

threshold of .13; R^2 explains 10.4% of the variance in the dependent variable of how age predicts the lipid screening interval.

Table 5

Coefficients with Age as the Independent Variable, Test Interval as Dependent Variable

Constant	B	Standard Error	Beta	t	Significance
Age	-.028	.005	-.323	-5.479	.0001
Gender	.332	.181	.108	1.838	.067

As age increases, the lipid testing interval decreases; for every one year increase in age, the interval decreases by .028 years. On average, the data showed less time passed between lipid tests for older patients. It should be noted that if a one-tailed analysis was done, then gender may also be found to represent some level of effect on screening intervals.

Examination of pooled data for the combined pretest and posttest of 493 cases showed 326/493 or 66% of patients were diagnosed as having some level of hyperlipidemia, 18% were diagnosed as having normal lipid levels, and 16% did not have lipid test results available. The prevalence of hyperlipidemia for the pooled study sample data (66%) is notably higher than the prevalence of 38% for all American adults with hyperlipidemia as defined by total cholesterol $\geq$ 200mg/dL (CDC, 2020). Nineteen patients with lipid levels for pooled pre/post cases met or exceeded the LDL-C $\geq$190mg/dL cut point for probable FH and was higher than the 1:250 expected prevalence for FH often cited in the literature (see Table 6). A z-score was calculated for two populations, comparing the proportion of FH cases found for the pretest and posttest groups to the expected population proportion of 1/250. The z-score was repeated using pooled

data (see Table 6), since there was no statistical difference between the pretest and posttest groups (see Table 3).

Table 6

Sample Proportions for Pretest, Posttest and Pooled Sample Populations

Probable number of FH cases	N	p-hat	z 2-tailed test	*p*
Pre-test 11	243	p-hat = 0.045	-21.2388	<.00001
Post-test 8	250	p-hat = 0.032	-21.6562	<.00001
Pooled 19	493	p-hat = 0.038	-25.8019	<.00001

Note. The probable FH cases in the project samples compared with the expected proportion for the general population of 1/250, exceeded expected values in all three categories of pretest, posttest and for pooled data. The result is significant at $p < .05$.

One of the 19 patients identified as probable FH had treatment ordered, with the remaining 18 not showing a treatment addressing elevated lipids entered into the EMR. Project goals did not include collecting data to explore treatment dynamics, such as patient declining to be tested or accept treatment.

Data to support addressing the fourth and final project goal of evaluating post-intervention impact were planned to be obtained using a Likert scale survey. Since no surveys were returned, the fourth goal could not be met.

Data Analysis and Discussion

The provider survey data to address the first project goal focused on changes in provider knowledge pre- and post-education. Analysis of results was necessarily confined to a listing of

incorrect responses to content questions. Further statistical analysis was not possible due to small sample size of the provider group and because pretest and posttest groups were not composed of the same members. Response rates for the pre/post intervention surveys were respectively 80% for both pre/ post-education surveys; the average score was 77% correct for pretest and posttest groups. Given the low number of total respondents and 50% change in participants who took both pre- and post-surveys, no meaningful conclusions could be reached about effects of the educational module. The most frequently missed questions were similar for both groups and can suggest topics to support further educational efforts (see Table1).

Case-based interactive discussions as an effective tool to enhance practice guideline adoption were not possible due to COVID-19 site restrictions. Consequently, evaluation of the educational intervention does not reflect the potentially beneficial effects of peer-to-peer interaction on introducing practice change (Bluestone, 2013). Increased patient volume, provider staffing turn-over, and major changes in clinic workflows due to the COVID-19 pandemic may have negatively impacted engagement with the educational content. Realization of the educational intervention program's full potential was likely further impeded by the project timeline allocating one month to introduce the new information without the opportunity for successive sessions to reinforce and facilitate clinical application. Multiple educational sessions over a longer period of time would have permitted collection of time-series data consistent with benchmarking for continued process improvement (Polit & Beck, 2021).

The EMR-based data collection process and online education delivery methods were a good fit for this study because they were low-cost, non-intrusive, and did not require participant cooperation by patients and a relatively low level of cooperation by providers. Data collection was accomplished remotely and relatively quickly through secure, cloud-based digital reporting

functions. Limitations of this project design included a larger data set than anticipated, missing data, digital report format incompatibility with research design, and potential researcher fatigue related to lengthy, multi-step record review that may have impacted consistency or accuracy.

Lipid screening data analysis for the pre/posttest groups showed no difference in the time interval from admission to first lipid screening between groups ($p = 0.976$) (see Tables 2 and 3). Multiple factors may account for this result, with a lack of adequate time and opportunities to deliver and measure data against benchmarks in a time-series manner consistent with a quality improvement design. Regression analysis demonstrated a correlation effect between age and lipid testing, with the testing interval decreasing by .028 years for every one-year increase in age. On average, less time passed between lipid tests for older patients. This finding suggests that the patients were tested more frequently as they increased in age. The $R^2 = .104$ explains 10.4% of the variance in the dependent variable of how age predicts the screening interval and is considered a small to medium level of effect since it is below the threshold of $R^2 = .13$ (Cohen, 1988). No correlation between lipid testing and gender was found ($p = 0.067$) (see Table 5).

The proportion of clinic patients exceeding the expected population estimate for FH was significant ($p < .001$) (see Table 6). This result exceeded the expected population proportion of 1/250 and also exceeded the 1/100 proportion for populations with high consanguinity (Zamora et al., 2017). The higher than expected proportion can be explained by how the diagnosis of FH was defined. As discussed earlier, a clinic's EMR database does not typically contain adequate information, such as family history and specific clinical and genetic data, to permit diagnosis of FH based on established such as the MEDPED or DLCN criteria. Nordestgaard et al. (2020) reported the 95th percentile for untreated LDL-C in the general population is approximately 190 mg/dL, so it is expected to find five out of 100, or 12.5 out of 250, which corresponds to the

levels found in this project (see Table 6). Zamora et al. (2017) defined FH by LDL-C thresholds, an approach consistent with the 2018 cholesterol management algorithm (ACC/AHA) cut-point of LDL-C >190mg/dL as the level at which clinicians need to consider elevated cholesterol has a genetic basis. While the genetic etiology of severely elevated cholesterol is still being elucidated, the literature supports the essential clinical practice of regarding patients meeting or exceeding the cut-point of 190mg/dL as being at a very high risk for early CVD; the recommendation is for providers to identify and treat these patients aggressively (Grundy et al., 2019; Hegele, 2020).

Recommendations

This primary care clinic project identified a greater-than-expected number of patients at risk for FH and a need for continued provider education. Implications for practice are site-specific and limited given the quality improvement project design. Additional time for serial benchmarking and modification of interventions to bring about stepwise improvements in outcome measures and strengthen practice may facilitate a more accurate evaluation of the educational intervention and project as a whole. Feedback from participants through the impact on practice survey was initially designed to provide additional input as to what extent aspects of the intervention are perceived to meet the DOI criteria of compatibility, trialability, simplicity, and relative advantage (Rogers, 2003). However, since no post-project impact survey instruments were returned, additional time to accommodate workflow and staffing challenges may result in a measurable return of clinical impact surveys, should the project be replicated.

Although lipid screening results did not show a change in pretest to posttest intervals, there were other findings that can inform current practice. While precise diagnosis of FH may not be practical in the primary care setting through EMR database searches, it does not take away from the fact that such searches can help identify patients exceeding the threshold for severe

hypercholesterolemia, treated as high risk for early heart disease and referred to lipid specialists as indicated. Should this project be revised and conducted over 1-3 years, it would be possible to better evaluate program effects on practice, adherence to guidelines, and clinical outcomes. Other avenues for future quality improvement or research might include examining patient attitudes towards lipid testing and treatment for adults and also for children who stand to gain the most benefit from early screening and intervention (Nordestgaard, 2013). Another promising approach could involve embedding digital EMR prompts to cue the provider when lipid levels exceed the 190mg/dl cut-point with treatment recommendations. Currently, lab values are not directly linked to the project site's EMR database. Since diagnosis codes for FH are a recent addition to the WHO ICD-10 code set (2016), it may also help to assess the level of provider familiarity with FH codes and provide reinforcement regarding the criteria for clinical application (The FH Foundation, 2016).

Conclusions

The potential benefits of effective screening and treatment for those at risk of FH are well described in the literature. Opportunities for process improvement have been identified in the project's primary care setting for improved awareness and screening for FH. The prevalence of high-risk patients has been reported. Next steps include continued data collection by the project site leadership with benchmarking and continued process improvement efforts to help translate the science into structured approaches that will help prevent the premature morbidity and mortality associated with familial hypercholesterolemia.

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Appendix A

Education to Promote Awareness and Screening for FH in Primary Care: Content Map

Educational Intervention DNP FH QI project			
Objective	**Content**	**Time Frame**	**Teaching Methods** (Long distance format)
A. **Explore rational for FH QI project for primary care** 1. assess baseline knowledge 2. what is FH; how is different 3. rationale for study	Introduce topic • Rationale for project -FH most common genetic metabolic disease -Tier 1 CDC genetic disorder - 90% undiagnosed, 20x higher risk CV events -early dx & treatment mitigate risk - why FH is different (d/t LDL receptor defect) -primary care as key gateway to preventive healthcare • Pre-test of knowledge about FH	**15 minutes**	• Introduction to program by PowerPoint (available to all staff • Administer pre-test during 1st week September via Survey Monkey to all providers
B. **Explore FH Dx & Tx** 1. Review pathophysiology 2. Epidemiology 3. Clinical presentation 4. Physical Exam 5. Diagnostic screening 6. Diagnosis & Tx	• Describe LDL receptor dysfunction -genetic mechanism; autosomal dominant • Prevalence • Initial presentation often w cardiac event • Early arcus, tendon xanthomas, often none • Lipid panel-fasting/non-fasting • For ≥20yrs, once q 5 yrs (Healthy People) • Suspect FH if treatment naïve LDL-C is ≥ 190 mg/dl • Introduce 2018 ACC/AHA Cholesterol Mgmt Guidelines to support FH screening	**30 minutes**	• During 2nd week September send out article by Elkins & Fruh (2019), post-test Email supplementary information - copy ACC/AHA guideline - laminated algorithm with application examples

	Resources for additional information	**5 min per week**	• Weekly brief project updates, opportunity to ask questions by email to participants • student contact info • references, supplementary FH information with weekly updates to end of data collection, end of November
7. Wrap up	• Recap project aims • Review key points • Elicit provider perception of impact on clinical practice • Where to get more information		During last week in November • Practice Impact survey after project completed. • Summary of project with thank you to clinic team sent by DNP student

Appendix B

Educational Program FH Knowledge Quiz

Circle the one best answer for each question below (to be sent via Survey Monkey):

(1) The LDL-C levels in patients with homozygous FH is most likely to be
- o **four times that of the general population level**
- o three times that of the general population level
- o two times that of the general population level

(2) Genetic mutations contribute to elevated LDL-C by
- o destroying hepatocytes
- o inhibiting elimination by the kidney
- o **inhibiting the receptors' ability to clear LDL-C from circulation**

(3) All of the following clinical presentations are suggestive of FH except
- o **corneal arcus before age 60**
- o fasting LDL-C 190mg/dl or greater
- o presence of xanthomas

(4) The most frequent initial clinical presentation or FH is atherosclerotic
- o cerebral vascular disease
- o **cardiovascular disease**
- o peripheral vascular disease

(5) Patients with homozygous FH are more likely to have which clinical presentation caused by **lipid** deposits?
- o aortic valve prolapse
- o mitral valve regurgitation
- o **supravalvular aortic stenosis**

(6) Cholesterol screening for patients with a family history of elevated cholesterol should begin at what age?
- o **2**
- o 5
- o 9

(7) Routine screening during adolescence is not recommended because the LDL-C level
- o Is falsely elevated
- o Is falsely lowered
- o **fluctuates during puberty**

(8) Which of the following is a secondary cause of elevated cholesterol?
- o hyperthyroidism
- o **hypothyroidism**
- o hypoparathyroidism

(9) If using the Friedewald equation, levels above 400mg/dl of which lipid component may decrease the accuracy of LDL-C readings?
- o **triglycerides**
- o total cholesterol
- o HDL-C

(10) Why are cardiovascular risk assessment tools not valid in patients with FH?
- o patients with FH already have premature cardiac disease
- o tools do not evaluate HDL-C levels
- o **tools underestimate the length of time patients are exposed to high levels of cholesterol**

(11) Which of the following lifestyle changes is not essential for patients with FH?
- o **aim for saturated fat intake of less than 10% of total calories**
- o manage diabetes mellitus
- o stop smoking

(12) When using statins to treat FH,
- o **due to reliance on LDLR, goal reduction with high-intensity classified statin drugs may be 25%**
- o high intensity statins will decrease the LDL-C level by 80%
- o When prescribed at the maximum moderate-intensity dose, statins may decrease LDL-C by 70%

(13) Which statement best describes the adverse reactions of statins?
- o adverse reactions are minimized with routine monitoring of ALT and AST levels
- o **approximately 1% of patients experience ALT and AST levels that are more than three times the upper limit of normal**
- o muscle symptoms are rare and associated with decreased kidney function

(14) Which non-statin therapy inhibits the absorption of cholesterol and has very few drug interactions?
- o colesevelam
- o **ezetimibe**
- o niacin

(15) Which second-line drug is a monoclonal antibody that can further reduce LDL-C by up to 60% when statins alone fail to meet the patient goal?
- o cholesterol inhibitor
- o **PCSK9 inhibitor**
- o triglyceride protein inhibitor

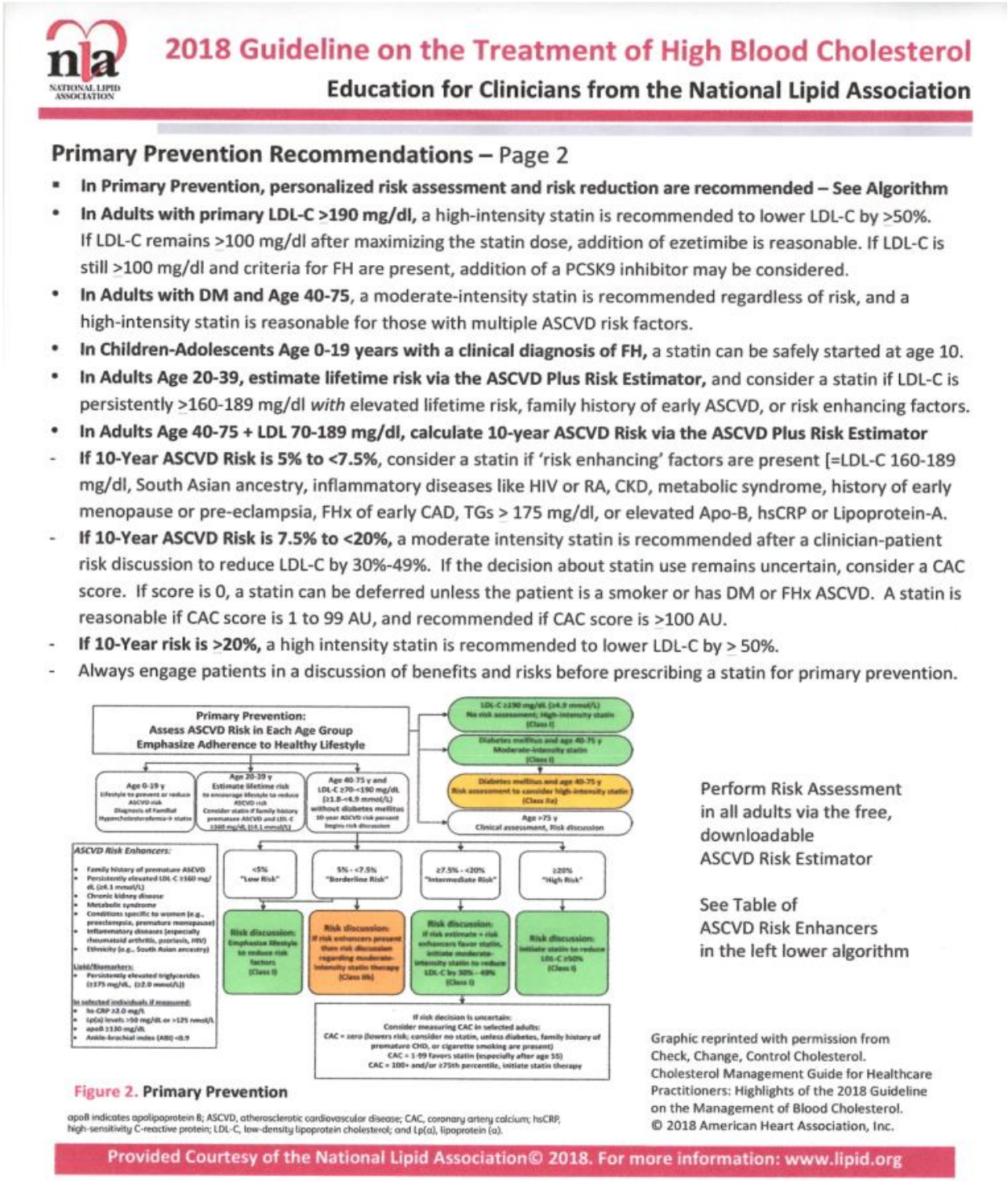
(16) Which therapy provides immediate reduction of LDL-C in patients with ASCVD who cannot tolerate pharmaceutical lipid-lowering therapies?
- o **apheresis**
- o partial ileal bypass
- o liver transplant

(17) Which statement best describes the purpose of cascade testing in patients with FH?
- o although costly, this family-centric screening helps determine the probability of FH in first-degree relatives
- o **cascade screening assists with earlier diagnosis in young relatives who many not otherwise have a cholesterol level checked**
- o cascade screening requires genetic testing by the index patients

(18) Which of the following teaching points is *not* appropriate for patients with FH?
- o dietary saturated fats should be decreased and consumption of fiber, fruits, and vegetables should be increased
- o encourage other family members to be tested for FH
- o **lipid specialists should manage all patients with FH**

Note. Questionnaire developed by Elkins and Fruh (2019).

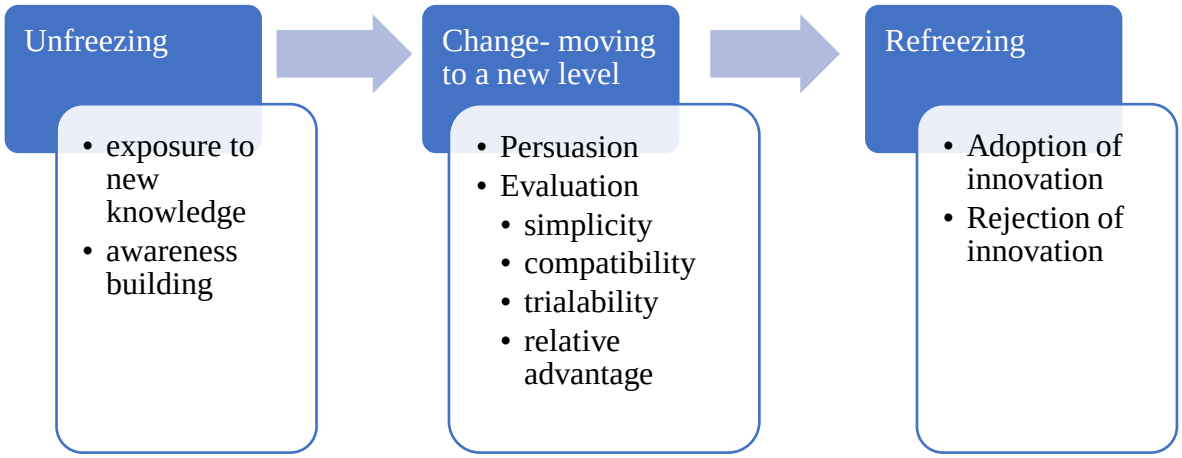
Appendix C



Note. Supplementary information on use of the algorithm will be provided during the intervention.

Appendix D

Application of Roger's Diffusion of Innovation and Lewin's Change Theoretical Models



= Lewin's stages of change

= Rogers diffusion process

Note. The diagram illustrates how Rogers' theoretical model adds elements of psychodynamic specificity to Lewin's classic Social Change model (Lewin, 1951; Rogers, 2003).

Appendix E

Post FH Project Evaluation of Impact on Practice

Your participation in this project to help improve screening in primary care for individuals with familial hypercholesterolemia is greatly appreciated. Your feedback is important to improving future education on this topic. Please answer all of the following questions. Thank you for your assistance.

My use of the information gained from the FH educational program:
(place an "X" under the most appropriate choice)

	Strongly Agree	agree	neutral	disagree	strongly disagree
improved my knowledge & understanding of the evidence Supporting lipid/FH screening	_____	_____	_____	_____	_____
modified the way I manage Patients	_____	_____	_____	_____	_____
Improved my understanding of Provide to my patients	_____	_____	_____	_____	_____
During a typical week when I am seeing patients, I consult the FH screening guideline/ algorithm from the FH education project	_____	_____	_____	_____	_____

Were you able to read the article & Complete the post-test? yes _____ no _____ If not, why_____
_____

Did you perceive any commercial Bias in the FH program content? yes _____ no _____
If so, please explain:_____

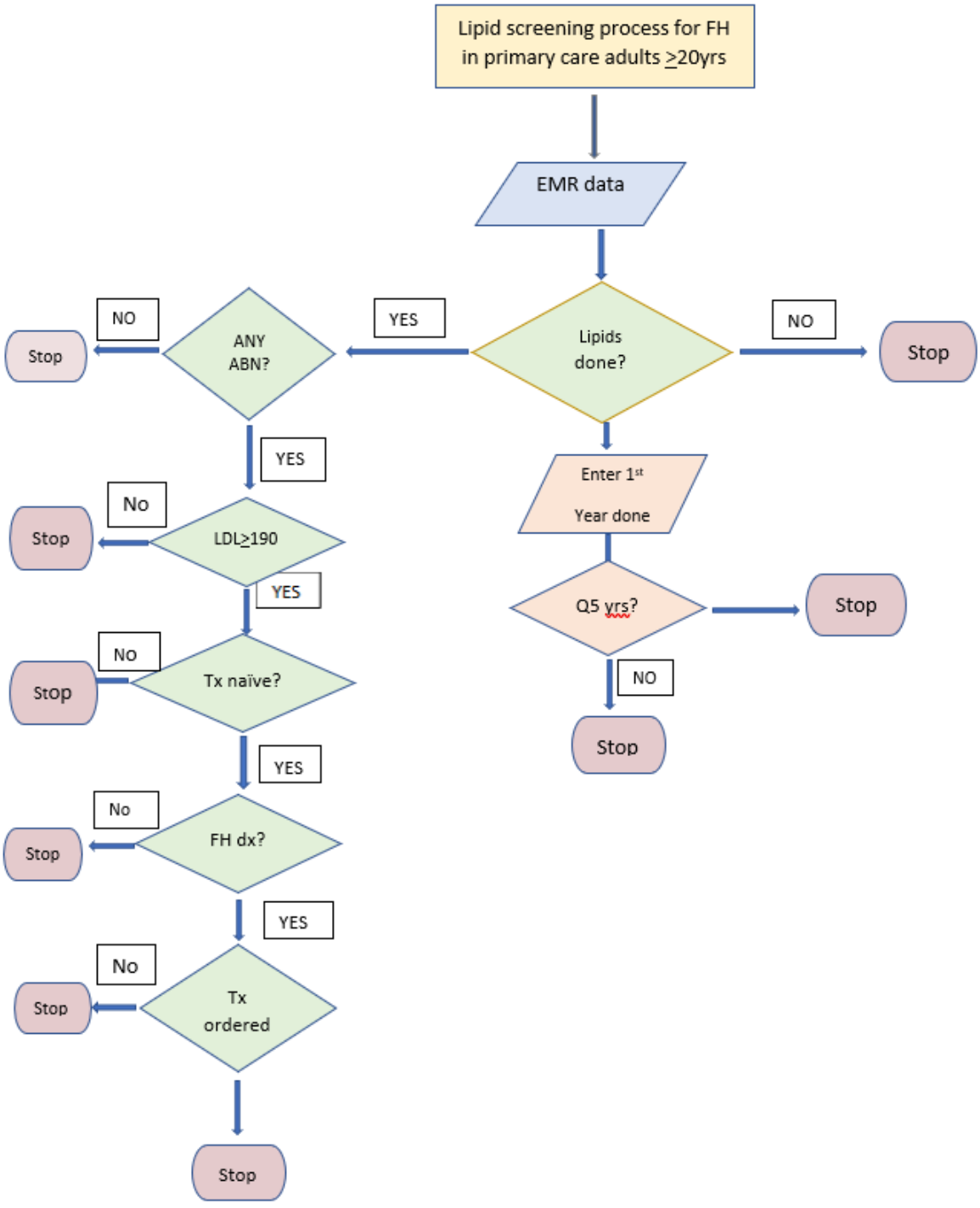
Are you a: Physician_____ Physician Assistant_____ Nurse Practitioner_____

Additional comments:_____
_____

Please return this survey by email by November 14th to: mnametka@zagmail.gonzaga.edu

Appendix F

EMR Data Extraction Flow Chart



Note. The data extraction flow was developed with input from the EMR data analyst team.