



Changes in Youth Cholesterol Screening Rates in an Academic Center During the COVID-19 Pandemic

Jessica K. Schwartz¹ · Xiao Zhang² · Amy L. Peterson²

Received: 22 January 2025 / Accepted: 12 March 2025

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2025

Abstract

Screening youth for hypercholesterolemia allows for detection of familial hypercholesterolemia that can predispose to premature heart disease, however guidelines provide conflicting recommendations regarding universal cholesterol screening. The COVID-19 pandemic and the perception of conflicting guideline recommendations (2011 National Heart, Lung, and Blood Institute guidelines and United States Preventive Services Task Force recommendations in 2016 and 2023) may have adversely affected youth cholesterol screening rates. This study examines screening rates during and after the COVID-19 pandemic and the most recent guideline update. Electronic health record data from a single academic institution was used to calculate Order Placement Rates (OPRs) for subjects aged 8 years 9 months–21 years from 3/18/2019 to 12/31/2023. Demographic data included subject sex, age, zip code, and primary provider's specialty. Zip codes were categorized as rural/urban and underserved/middle/advantaged. The study period was divided into five stages (pre-pandemic, mid-pandemic, late-pandemic, post-pandemic, and post-guideline). Relative to baseline OPR prior to 3/18/2019, study period OPRs decreased slightly in pre-pandemic (73.3%), mid-pandemic (70.9%), and late-pandemic (65.4%) stages, with sharper declines during post-pandemic (47.6%) and post-guideline stages (35.2%). OPR decreased more significantly for youth 9–11 years than 17–21 years (post-guideline OPR: 35.1% versus 46.9%). Urban underserved and urban advantaged had higher OPRs. OPRs for family medicine and pediatrics declined ($p < 0.01$), more significantly in pediatrics (post-guideline versus pre-pandemic OPR adjusted odds ratio [95% CI] = 0.03 [0.02–0.04] for pediatrics, 0.35 [0.30–0.40] for family medicine). Our institution showed decreases in cholesterol screening OPRs after both the COVID-19 pandemic and guideline update. OPRs dropped most significantly among youth aged 9–11 years and among pediatric providers. Urban youth were more likely to be screened than rural youth. Discrepancies persist among access to youth cholesterol screening.

Keywords Pediatric cholesterol screening · Familial hypercholesterolemia · Pediatric health maintenance · Clinician behavior · Social determinants health

Abbreviations

OPR	Order placement rate
FH	Familial hypercholesterolemia
LDL-C	Low-density lipoprotein cholesterol
ASCVD	Atherosclerotic cardiovascular disease
NHLBI	National heart, lung, and blood institute
AAP	American academy of pediatrics

USPSTF	United States preventive services task force
EHR	Electronic health record
HDL-C	High-density lipoprotein cholesterol
BMI	Body mass index

Introduction

Familial hypercholesterolemia (FH) is an autosomal dominant disorder that causes increased levels of low-density lipoprotein cholesterol (LDL-C) and predisposes to premature atherosclerotic cardiovascular disease (ASCVD). Although FH is relatively common, with an estimated prevalence of 1 in 300 individuals across most populations, it remains significantly underdiagnosed [1–4]. Early detection of the FH phenotype allows for early treatment via lifestyle

✉ Amy L. Peterson
apeterson@pediatrics.wisc.edu

¹ Department of Pediatrics, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

² Division of Pediatric Cardiology, Department of Pediatrics, University of Wisconsin School of Medicine and Public Health, CSC H6/528 MC 4108, 600 Highland Ave., Madison, WI 53792, USA

modification and cholesterol-lowering medications (usually statins), which ameliorates most of the excess risk of premature ASCVD and cardiac death [2, 5–7]. A universal screening strategy among youth can help increase the detection rate for FH. The National Heart, Lung, and Blood Institute (NHLBI) issued guidelines in November 2011 recommending universal cholesterol screening for youth between ages 9 and 11 years and again between 17 and 21 years old. These guidelines were endorsed by the American Academy of Pediatrics (AAP) on December 1, 2011 [8]. However, in 2016 and reinforced again in 2023, the United States Preventative Services Task Force (USPSTF) gave an “I” recommendation for universal youth cholesterol screening, indicating evidence was insufficient to recommend for or against universal screening [9, 10]. Our group documented substantial changes in our institution’s youth cholesterol screening rates between 2011 and 2019 that coincided with release of the NHLBI/AAP guidelines in 2011 and the USPSTF statement in 2016, illustrating the importance of clear direction in guidelines and provider education [11, 12]. Studies have shown differing screening rates based on demographic and clinical factors of eligible youth, such as payer type [13], ordering provider specialty [11, 14], and the presence of a high-risk medical condition [15].

In 2020, the COVID-19 pandemic interrupted routine health care access and utilization. It is unclear how the pandemic might have impacted youth cholesterol screening rates. The purpose of this study was to examine youth cholesterol screening rates throughout the period of the COVID-19 pandemic and the most recent USPSTF guideline release. We hypothesized that screening rates may have dropped during the COVID-19 pandemic due to reasons mentioned above and continued to decrease after the release of the most recent USPSTF recommendation.

Materials and Methods

Data extraction from the electronic health record (EHR) of a not-for-profit academic institution was performed for subjects aged 8 years 9 months to 21 years old who presented for a health maintenance visit between 3/18/2019 and 12/31/2023. Youth up to 21 years of age were included to reflect the ages for which the 2011 NHLBI guideline provided cholesterol screening recommendations. Eight years 9 months old was chosen as the youngest age in order to capture youth who had a 9-year-old health maintenance visit prior to their ninth birthday. This 3-month buffer was included in our prior studies of youth cholesterol screening [11, 12]. Subjects were included in data analysis if they had no prior cholesterol screen (here, no prior laboratory result for high-density lipoprotein cholesterol [HDL-C] in their EHR) and had at least one prior health maintenance

visit documented in the EHR in the previous 3 years. HDL-C was chosen as the laboratory result indicating a cholesterol screen had taken place as it is part of both a full cholesterol panel and a nonfasting screen performed with measurement of total cholesterol and HDL-C in order to calculate non-HDL-C. This approach eliminated youth who were screened improperly with only total cholesterol measured (which does not allow for determination of HDL-C or calculation of non-HDL-C [8]), or youth who had an isolated triglyceride level measured as a part of a nutritional assessment. We further excluded subjects whose cholesterol screen was ordered by providers from specialties other than pediatrics and family medicine in order to avoid cholesterol panels that were ordered as part of a diagnostic evaluation. A subject was considered to have had a cholesterol screen “ordered” if an order for HDL-C was placed in the EHR at least once during the study period. Order placement rate (OPR) was calculated as a percentage of subjects eligible for screening who had an HDL-C order entered into the EHR. The Institutional Review Board reviewed and approved the study.

Demographic data collected from the EHR included sex, age at date of the health maintenance visit, self-reported race and ethnicity, body mass index (BMI) percentile, and zip code of subject’s current address. Each zip code for patients residing in Wisconsin was categorized as rural or urban, and as underserved, middle or advantaged in terms of health care based on groups outlined by the Wisconsin Collaborative for Healthcare Quality [16], which used factors such as health care providers, insurance status, and poverty level to classify Wisconsin zip codes. The specialty of the provider for the health maintenance visit was recorded (family medicine or pediatrics).

We divided the study period into five stages based on the date of the subject’s health maintenance visit: (1) pre-pandemic (3/18/2019–3/17/2020), (2) mid-pandemic (3/18/2020–3/17/2021), (3) late-pandemic (3/18/2021–3/17/2022), (4) post-pandemic (3/18/2022–7/18/2023), and (5) post-guideline (USPSTF update) (7/19/2023–12/31/2023). The pre-, mid-, late-, and post-pandemic stages were defined as consecutive years from the date that school closures in Wisconsin were mandated due to onset of the COVID-19 pandemic. The final post-USPSTF update time period was determined based on the date that USPSTF published their updated recommendation for universal youth cholesterol screening [10].

Simple descriptives on youth cholesterol testing OPR and demographic factors were calculated. Multivariate logistic regression models, stratified by the department of the ordering provider, were performed to examine OPR across the pandemic stages, rural/urban status, and obesity status, with adjustment for demographic factors. All analyses were conducted with the statistical software R 4.0.1 and STATA/SE

16.1. A *p*-value of less than 0.05 was considered statistically significant.

Results

In total, 15,788 subjects met the inclusion criteria for the study period and were included in the analysis. Their demographic characteristics are described in Table 1. There was a slightly higher percentage of males than females (51.5% versus 48.4%), and approximately half the subjects were between 9 and 11 years old. Most of the population was White (79.2%), non-Hispanic (90.5%), and resided in urban areas (70.9%). The majority (64.8%) of subjects had their health maintenance visit with a Family Medicine physician, with the remainder (35.2%) having their visit with Pediatricians.

Table 1 Patient demographics (*N* = 15,788)

	<i>n</i> (%)
Sex	
Male	8,137 (51.5)
Female	7,649 (48.4)
Age (years)	
9–11	7,986 (50.6)
12–16	5,230 (33.1)
17–21	2,572 (16.3)
Race	
American Indian or Alaska native	66 (0.4)
Asian	704 (4.5)
Black or African American	1,187 (7.5)
Native Hawaiian or other pacific islander	19 (0.1)
White	12,510 (79.2)
Multiple races or unknown	1,302 (8.2)
Ethnicity	
Hispanic/Latino	1,350 (8.6)
Not Hispanic/Latino	14,218 (90.5)
Unknown	152 (0.9)
Zip code category	
Urban underserved	346 (2.2)
Urban middle	1,175 (7.4)
Urban advantaged	9,671 (61.3)
Rural underserved	163 (1.0)
Rural middle	2,794 (17.7)
Rural advantages	1,469 (9.3)
Provider department	
Family medicine	10,233 (64.8)
Pediatrics	5,555 (35.2)
BMI category	
< 95th percentile	13,075 (82.8)
≥ 95th percentile	2,688 (17.0)

Across the five stages, the overall unadjusted OPRs decreased slightly from the pre-pandemic (73.3%) and mid-pandemic (70.9%) to late-pandemic (65.4%) stages, with a more substantial decline during the post-pandemic stage (47.6%, Fig. 1) and again during the post-USPSTF guideline stage (35.2%). The OPR trend was similar for youth aged 9–11 years, but different compared to OPRs for those aged 17–21 years, where the OPR increased slightly and then decreased. Interestingly, during the pre-pandemic stage, youth aged 9–11 years had the highest OPR compared to other age groups; however, by the post-USPSTF guideline stage, the OPR among 9–11-year-olds (35.1%) is lower than for 17–21-year-olds (46.8%).

Figures 2 and 3 show OPRs based on urban/rural status and subjects' BMI percentile over time. In general, urban underserved and urban advantaged had higher OPRs than other categories for a given time period, while urban middle had the lowest OPR. Youth with BMI ≥ 95th percentile had higher OPR than their peers with BMI < 95th percentile over the entire study period.

After adjustment for demographic factors, we found significant decreases in OPR for both family medicine and pediatrics providers over time ($p < 0.01$, Table 2). The drop was more significant in pediatrics compared to family medicine, with post-USPSTF versus pre-pandemic OPR adjusted odds ratio (95% CI) of 0.03 (0.02–0.04) for pediatrics and 0.35 (0.30–0.40) for family medicine. For both specialties, youth with BMI ≥ 95th percentile were more likely to have cholesterol screening ordered compared to youth with BMI < 95th percentile ($p < 0.05$). For family medicine, youth living in urban middle, rural underserved, rural advantaged, and rural middle areas were less likely to receive an order for cholesterol screening ($p < 0.05$). No difference across the urban/rural or disadvantaged/middle/advantaged categories was observed for pediatrics.

Discussion

This study demonstrates a dramatic reduction in placement of youth cholesterol screening orders in the EHR of a single institution. The decrease in cholesterol screening rates during the pandemic stages is consistent with the observed decline in other preventive practices during the COVID-19 pandemic [17]. Our institution has previously reported high youth cholesterol screening rates [11, 12] relative to other studies of youth cholesterol screening in the United States [4, 18–20] but lower rates than have been achieved in other countries, including Slovenia [21, 22], Germany [21], Japan [23] where “opt-out” approaches in primary care offices (Slovenia) or in schools (Japan) have been utilized. Interestingly, the post-pandemic and post-USPSTF stages saw more dramatic reductions in OPR compared to the mid- and

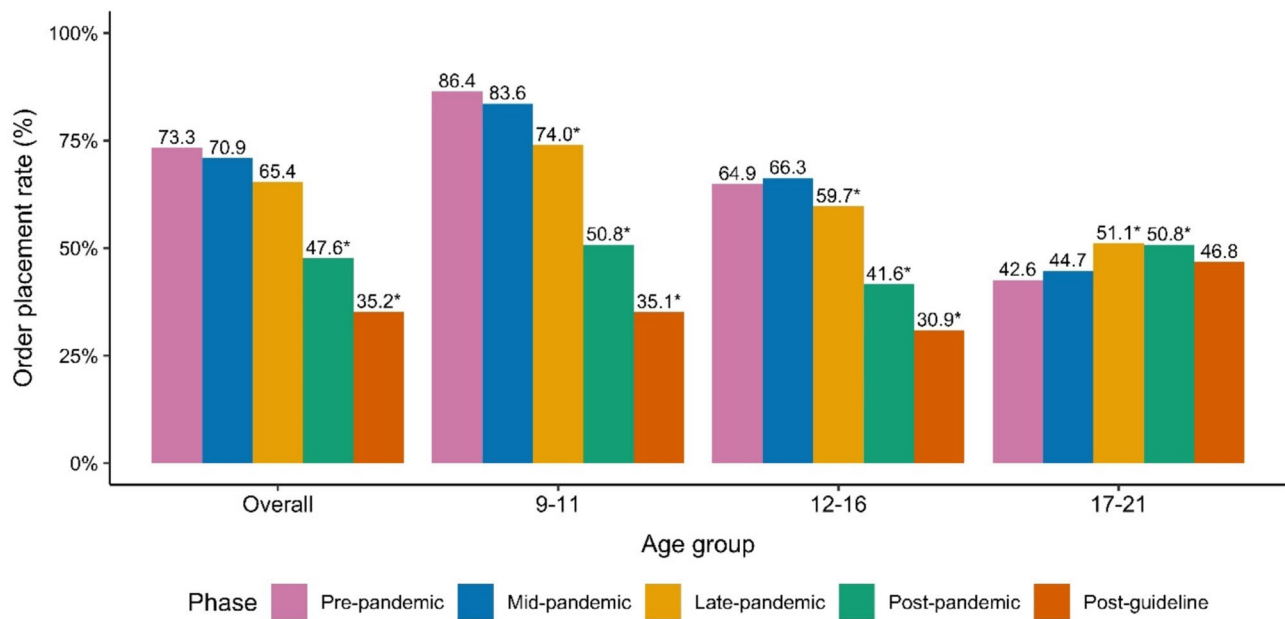


Fig. 1 Order placement rate for youth cholesterol screening by age and time period. * indicates OPR that is statistically significantly different compared to pre-pandemic rate ($p < 0.05$)

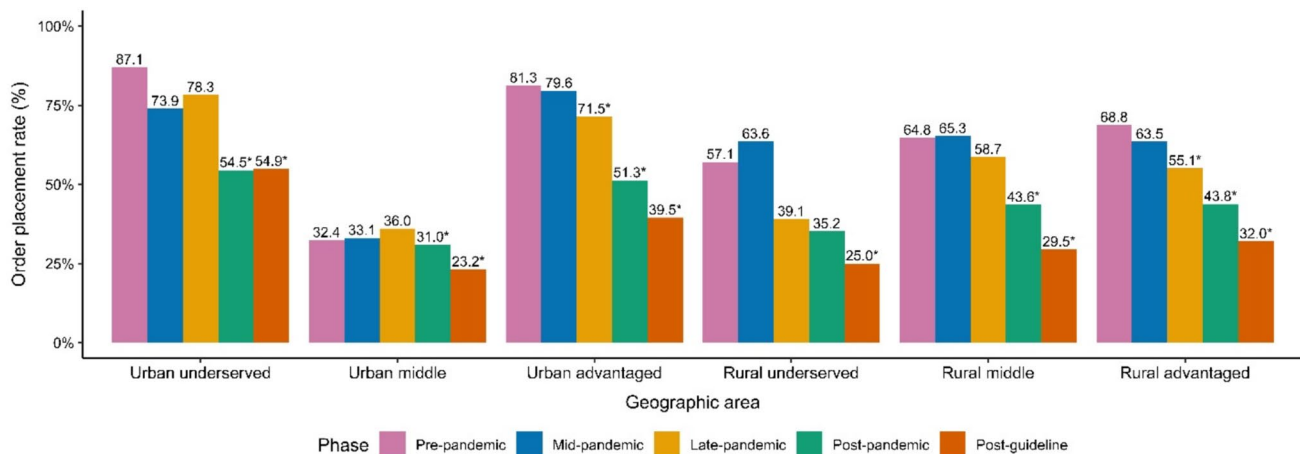


Fig. 2 Order placement rate for youth cholesterol screening by geographic area and advantaged status. * indicates OPR that is statistically significantly different compared to pre-pandemic rate ($p < 0.05$)

late-pandemic stages. These results suggest that there may be factors beyond simply the disruptions in health maintenance attributable to the COVID-19 pandemic (e.g., the perception of conflicting guidelines) that are responsible for the drop in the screening rates.

Our previous research found that after the 2011 release of guidelines from the NHLBI and AAP that encouraged universal youth cholesterol screening, our institution developed health care provider educational initiatives and modifications to the EHR that provided reminders and facilitators for youth cholesterol screening and subsequently observed a

significant increase in screening rates [12]. After the release of the 2016 USPSTF “I” recommendation for universal cholesterol screening and also after the 2018 American Heart Association/American College of Cardiology cholesterol management guidelines that gave universal cholesterol screening a IIb recommendation [24], we found a decrease in screening rates [11]. Therefore, we speculate that the drop in the screening rates during the post-pandemic and post-USPSTF guideline stages could be related. While more research is needed to further examine factors contributing to the decline, the low OPR by the post-USPSTF guideline stage

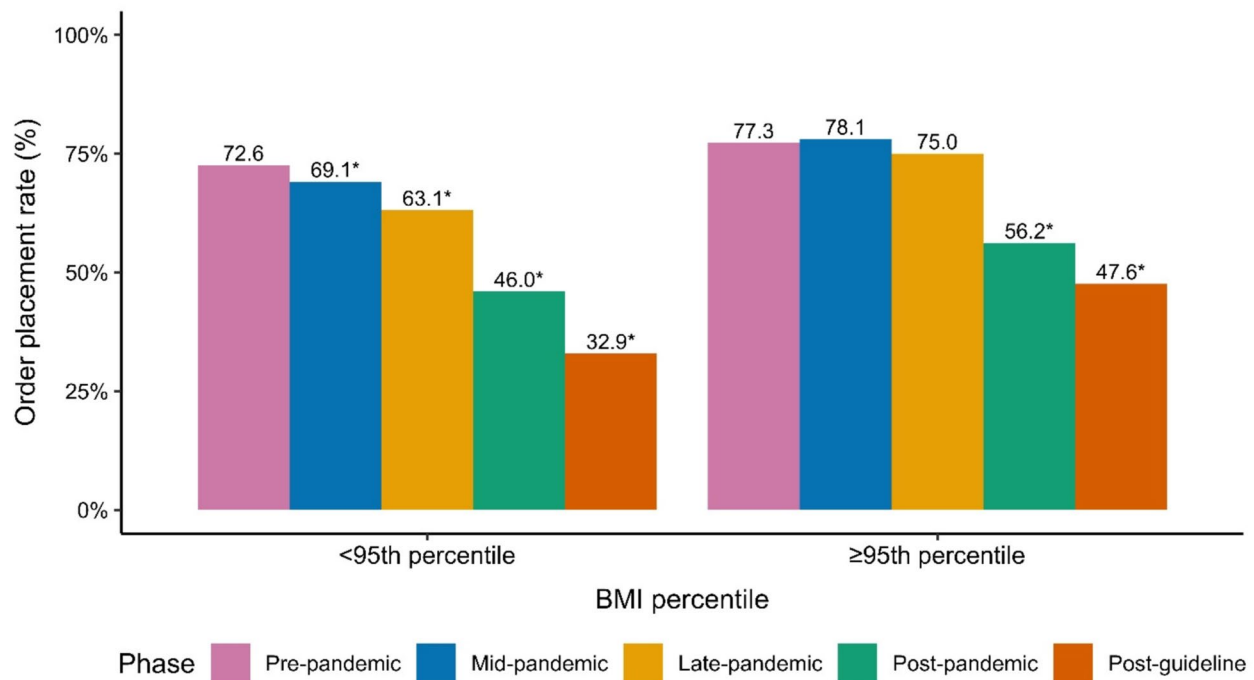


Fig. 3 Order placement rate for youth cholesterol screening by youth's BMI percentile. * indicates OPR that is statistically significantly different compared to pre-pandemic rate ($p < 0.05$)

Table 2 Comparison of cholesterol screening across pandemic stages between 2019 and 2023 ($N = 15,788$)

	Family medicine $N = 10,233$ AOR (95% CI)	Pediatrics $N = 5555$ AOR (95% CI)
Pandemic stages		
Pre	Ref	Ref
Mid	0.91 (0.77–1.08)	0.53 (0.35–0.83)
Late	0.75 (0.65–0.87)	0.27 (0.19–0.39)
Post	0.49 (0.43–0.56)	0.07 (0.05–0.10)
Post-USPSTF Update	0.35 (0.30–0.40)	0.03 (0.02–0.04)
Urban/rural status		
Urban underserved	Ref	Ref
Urban advantaged	0.71 (0.50–1.01)	1.28 (0.87–1.89)
Urban middle	0.25 (0.17–0.37)	0.92 (0.47–1.81)
Rural underserved	0.37 (0.23–0.62)	0.76 (0.22–2.58)
Rural advantaged	0.52 (0.35–0.75)	1.58 (0.96–2.60)
Rural middle	0.55 (0.38–0.79)	1.22 (0.78–1.92)
BMI		
<95th percentile	Ref	Ref
≥95th percentile	1.93 (1.73–2.16)	1.93 (1.55–2.40)
Unknown	1.71 (0.69–4.22)	NA

Bold values represent significance at $p < 0.05$. Models were also adjusted for race, ethnicity, sex, and age.

warrants concern and attention. If fewer youth with severe elevations in cholesterol like FH are detected, they cannot access appropriate and timely treatment; and in turn, their family or relatives may miss the opportunity to be detected via cascade screening. This leads to unnecessary premature ASCVD events and deaths that are entirely preventable.

The AAP released clinical practice guidelines for evaluation and treatment of youth with obesity in January 2023 which recommended cholesterol testing for youth ≥ 10 years old with overweight and obesity, while noting that cholesterol testing for youth 2–9 years old with obesity “may be considered” [25]. We did note OPRs were higher for youth with BMI ≥ 95 th percentile relative to youth with BMI < 95 th percentile throughout the study period. However, despite this guidance, in our institution we noted similar downward trends in OPR for youth both with and without obesity, suggesting this guideline did not significantly impact cholesterol screening behavior.

Overall, OPRs for pediatricians dropped more significantly than those for family medicine during the study period, but the OPRs for pediatricians were still higher than for family medicine throughout the study period. This is consistent with our previous study which showed a persistent gap in OPRs between the two groups from 2010 to 2019 [11]. We conducted a survey in 2019 among clinicians from these two specialties and found differences in the knowledge, attitude, and practices of pediatric cholesterol screening. For example, pediatricians were more familiar with the 2011

NHLBI/AAP guidelines, more likely to consider cholesterol screening a high priority item, and were less likely to have uncertainty about how to manage abnormal cholesterol results [14]. This is problematic, as it contributes to discrepancies in pediatric care by clinicians from different specialties.

This study is subject to limitations. The retrospective and observational nature of the study does not allow the establishment of a causal relationship. Our data is from a single institution and therefore may not be generalizable to practices across the United States. Nevertheless, it suggests that a decrease in youth cholesterol screening rates may have been impacted by disruptions due to the COVID-19 pandemic, but decreased rates also correlate with guideline release.

Conclusion

Our institution demonstrated a decline in youth cholesterol screening, especially after the COVID-19 pandemic and release of the 2023 “I” recommendation from USPSTF. Childhood represents a time period during which FH can be readily diagnosed and treated, and cascade screening of potentially affected family members can also be performed. Our study demonstrates persistent discrepancies in youth cholesterol screening rates based on the specialty of the ordering provider. Public health efforts are needed to identify opportunities to increase cholesterol screening rates among youth and to reduce premature ASCVD events and death.

Author Contributions AP and XZ: conceptualized the study. JS and XZ: acquired and analyzed the data. AP and XZ: interpreted the data. JS: wrote the main manuscript text, and AP and XZ: revised the manuscript. XZ and JS: prepared the tables and figures. All authors reviewed the manuscript.

Data Availability Data sets are not publicly available due to subject privacy, but a limited data set will be made available upon request, provided appropriate institutional review board approvals and data use agreements are provided.

Declarations

Conflict of interest The authors declare no competing interests.

References

- de Ferranti SD, Rodday AM, Mendelson MM, Wong JB, Leslie LK, Sheldrick RC (2016) Prevalence of familial hypercholesterolemia in the 1999 to 2012 United States national health and nutrition examination surveys (NHANES) clinical perspective. *Circulation* 133(11):1067–1072
- Nordestgaard BG, Chapman MJ, Humphries SE, Ginsberg HN, Masana L, Descamps OS et al (2013) Familial hypercholesterolaemia is underdiagnosed and undertreated in the general population: guidance for clinicians to prevent coronary heart disease: consensus statement of the European atherosclerosis society. *Eur Heart J* 34(45):3478–3490
- Kaestner TL, Bento VF, Pazin DC, Baena CP, Olandoski M, Abreu GA et al (2018) Prevalence of high cholesterol levels suggestive of familial hypercholesterolemia in Brazilian adolescents: data from the study of cardiovascular risk in adolescents. *J Clin Lipidol* 12(2):403–408
- Cortez AB, Salvador M, Li Q, Briscoe A (2024) Universal lipid screening in adolescents to identify familial hypercholesterolemia in a large healthcare system. *J Clin Lipidol* 18(2):e166–e175
- Goldberg AC, Hopkins PN, Toth PP, Ballantyne CM, Rader DJ, Robinson JG et al (2011) Familial hypercholesterolemia: screening, diagnosis and management of pediatric and adult patients: clinical guidance from the national lipid association expert panel on familial hypercholesterolemia. *J Clin Lipidol* 5(3 Suppl):S1–8
- McGill HC, McMahan CA, Gidding SS (2008) Preventing heart disease in the 21st century: implications of the pathobiological determinants of atherosclerosis in youth (PDAY) study. *Circulation* 117(9):1216–1227
- Luirink IK, Wiegman A, Kusters DM, Hof MH, Groothoff JW, de Groot E et al (2019) 20-Year follow-up of statins in children with familial hypercholesterolemia. *N Engl J Med* 381(16):1547–1556
- Daniels SR, Benuck I, Christakis DA, Dennison BA, Gidding SS, Gillman MW, et al (2011) Expert panel on integrated guidelines for cardiovascular health and risk reduction in children and adolescents: summary report. *Pediatrics* 128 (Suppl 5):S213–S256
- Bibbins-Domingo K, Grossman DC, Curry SJ, Davidson KW, Epling JW Jr, Garcia FA et al (2016) Screening for lipid disorders in children and adolescents: US preventive services task force recommendation statement. *JAMA* 316(6):625–633
- Force UPST (2023) Screening for lipid disorders in children and adolescents: US preventive services task force recommendation statement. *JAMA* 330(3):253–260
- Peterson AL, Zhang X, Dodge A, Eickhoff J, DeSantes K, Larson M et al (2021) Differences in pediatric cholesterol screening rates between family physicians and pediatricians correlate with conflicting guidelines. *Prev Med* 153:106732
- DeSantes K, Dodge A, Eickhoff J, Peterson AL (2017) Improving universal pediatric lipid screening. *J Pediatr* 188:87–90
- Hartz JC, Yellen E, Baker A, Zachariah J, Ryan H, Griggs SS et al (2019) The relationship between payer type and lipid outcomes in response to clinical lifestyle interventions in youth with dyslipidemia. *BMC Pediatr* 19(1):217
- Zhang X, DeSantes K, Dodge A, Larson M, Eickhoff J, Moreno M et al (2021) Practices and Attitudes regarding pediatric cholesterol screening recommendations differ between pediatricians and family medicine clinicians. *Pediatr Cardiol* 43(3):631–635
- Berger JH, Chen F, Faerber JA, O’Byrne ML, Brothers JA (2021) Adherence with lipid screening guidelines in standard- and high-risk children and adolescents. *Am Heart J* 232:39–46
- ZIP Codes by Rural and Urban Groupings Toolkit. In: Program HI, editor. Madison, WI: University of Wisconsin-Madison, 2020.
- Hill HAYD, Elam-Evans LD et al (2024) Decline in vaccination coverage by age 24 months and vaccination inequities among children born in 2020 and 2021—national immunization survey-child, United States, 2021–2023. *MMWR Morb Mortal Wkly Rep* 73:844–853
- Thompson-Paul AM, Kraus EM, Porter RM, Pierce SL, Kompaniyets L, Sekkarie A et al (2024) Pediatric lipid screening prevalence using nationwide electronic medical records. *JAMA Netw Open* 7(7):e2421724
- Valle CW, Binns HJ, Quadri-Sheriff M, Benuck I, Patel A (2015) Physicians’ lack of adherence to national heart, lung, and blood

- institute guidelines for pediatric lipid screening. *Clin Pediatr (Phila)* 54(12):1200–1205
20. Mihalopoulos NL, Stipelman C, Hemond J, Brown LL, Young PC (2018) Universal lipid screening in 9- to 11-year-olds before and after 2011 guidelines. *Acad Pediatr* 18(2):196–199
 21. Sustar U, Kordonouri O, Mlinaric M, Kovac J, Arens S, Sedej K et al (2022) Universal screening for familial hypercholesterolemia in 2 populations. *Genet Med*. <https://doi.org/10.2139/ssrn.4035402>
 22. Groselj U, Kovac J, Sustar U, Mlinaric M, Fras Z, Podkrajsek KT et al (2018) Universal screening for familial hypercholesterolemia in children: the Slovenian model and literature review. *Atherosclerosis* 277:383–391
 23. Matsunaga K, Mizobuchi A, Ying FuH, Ishikawa S, Tada H, Kawashiri MA et al (2022) Universal screening for familial hypercholesterolemia in children in Kagawa. *Jpn J Atheroscler Thromb* 29(6):839–849
 24. Grundy SM, Stone NJ, Bailey AL, Beam C, Birtcher KK, Blumenthal RS et al (2019) 2018 AHA/ACC/AACVPR/AAPA/ABC/ACPM/ADA/AGS/APhA/ASPC/NLA/PCNA guideline on the management of blood cholesterol a report of the American college of cardiology/American heart association task force on clinical practice guidelines. *J Am Coll Cardiol* 73(24):e285–e350
 25. Hampl SE, Hassink SG, Skinner AC, Armstrong SC, Barlow SE, Bolling CF et al (2023) Clinical practice guideline for the evaluation and treatment of children and adolescents with obesity. *Pediatrics*. <https://doi.org/10.1542/peds.2022-060640>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.