

## **Feasibility and Parental Attitudes to Universal Cholesterol Screening in Paediatric In-Patients**

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### **Abstract**

#### **Aims**

Dyslipidaemia is a treatable risk factor for atherosclerosis, and the 2011 National Heart, Lung and Blood Institute (NHLBI) guidelines recommend universal lipid screening at 9-11 years. This study aimed to assess the number of children with cardiovascular disease risk factors and parental attitudes regarding cholesterol screening and management.

#### **Methods**

Parents of children aged 3-14 years admitted to the paediatric wards at University Hospital Limerick received questionnaires over a 4-week period. Data collected included demographics, cardiovascular risk factors, and parental attitudes to lipid screening and management.

#### **Results**

A total of 53 parents completed the questionnaire survey and of those 40% (n=21) of patients met criteria for targeted screening, while 53% (n=30) met criteria for screening as per NHLBI guidelines. Restriction to those aged 9 and over resulted in 100% (n=26) being screened based on NHLBI guidelines with 38% (n=10) being screened using targeted screening. Ninety eight percent of respondents (n=52) had no objection to lipid analysis being performed.

#### **Conclusion**

A significant proportion of children would not be included with targeted screening that would be included on screening as defined by the NHLBI guidelines. Almost all the of study group had no issue with lipid testing being carried out and so may be an avenue for future intervention to help prevent development of cardiovascular disease.

## Introduction

Dyslipidaemia is a risk factor for atherosclerosis, which is an early step in the development of cardiovascular disease (CVD) <sup>1 2</sup>. The process of atherosclerosis begins in childhood and causes cardiovascular morbidity due to coronary artery disease, stroke, and peripheral arterial disease <sup>3 4</sup>. In addition to dyslipidaemia, other risk factors for the development of atherosclerosis and CVD include obesity, hypertension, smoking, hyperglycaemia, and a positive family history of CVD. The severity of atherosclerotic plaques in adults correlates positively with the duration of the dyslipidaemia and as a result early intervention in children with dyslipidaemia has been recommended as a preventative therapy against CVD development, although the issue of screening and exact treatment remains controversial <sup>5 6</sup>.

In 2011 the National Heart, Lung and Blood Institute (NHLBI) Expert panel formulated guidelines for Cardiovascular health and risk reduction in children, recommending age-dependent universal screening for children between 9-11 years, as opposed to targeted screening, which had previously been recommended <sup>7 8</sup>. These recommendation changes were considered the best method of identifying all children with severe dyslipidaemia and allow for the earliest treatment and follow-up <sup>5 6</sup>. The guidelines differ from the selective screening recommended of children and adolescents by the 2007 US Preventive Services Task Force <sup>4</sup>. Screening variables in selective processes include, a positive family history of cardiovascular disease or dyslipidaemia, or where family history is unknown, any patient with any risk factor associated with CVD which include obesity, hypertension, diabetes, or tobacco usage. Recent studies have shown that screening only patients with risk factors fails to identify some patients with genetic or acquired dyslipidaemias <sup>8</sup>. Addressing childhood dyslipidaemia is of significant public health importance due to the high mortality rate associated with CVD, and this is particularly true within the Irish population.

We report a pilot questionnaire-based study, on a general paediatric in-patient population at University Hospital, Limerick (UHL). UHL is a university-affiliated regional paediatrics unit, serving a catchment area of approximately 1.1 million people. The aims of this study were to evaluate the incidence of CVD risk factors within a general paediatrics hospital inpatient population and to explore issues relating to parental concerns or barriers to undertaking universal screening for dyslipidaemia.

## Methods

A questionnaire was designed based on the NHLBI Expert panel guidelines recommendations for paediatric lipid screening <sup>7</sup>, and was formulated to investigate the number of cardiovascular risk factors within the patient cohort including; family history of CVD, tobacco exposure at home, self-reported history of hypercholesterolaemia in parents, current diagnosis of diabetes mellitus, hypertension, or any other reported condition pre-disposing to secondary dyslipidaemia. Patient demographic data including age, height and weight was collected where possible. The questionnaire also examined specific questions regarding parental concerns to having additional blood samples taken for lipid analysis and also regarding willingness to attend a dietician for diet and lifestyle advice and additionally, if there were issues with the use of a lipid lowering medications.

The questionnaire was validated, and a pilot-study was conducted on a sub-sample of the target population, with the questionnaire revised subsequently for any ambiguity.

Pilot data was excluded from the final analysis. The survey required an average of 5 minutes to complete. This study was approved ethically by the University Hospital Limerick ethical committee.

Inclusion criteria included: the ability to speak and understand English, parents being present at the time of interview and being admitted onto the paediatrics ward at UHL. Exclusion Criteria included: the inability to speak and understand English and where siblings had already participated in the study. Patients were not excluded on the basis of medical background. The lower limit of 3 years was chosen as screening is not recommended below this age, while the upper limit of 14 was chosen as this is the age limit for admission of newly diagnosed patients to the Paediatrics ward at UHL.

The sample method consisted of systematically approaching the parents/guardians of patients who were inpatients within the Paediatrics ward at UHL over the course of the sampling period. The questionnaires were completed over a 4-week period in February 2015. Parental consent was obtained, and answers were self-reported. The completed questionnaire data was coded into SPSS version 20 for further analysis. An overall summary of the questionnaire data was analysed, and summary data compiled.

## **Results**

### *Number of questionnaires*

A total of 66 patients fulfilling the inclusion criteria were admitted during the study period, of whom 63 consented to participate and 3 declined. Fully completed questionnaires were returned by 53/63 parents/guardians (84%). The majority (over 75%) of the questionnaires were returned without a weight or height recorded and as a result BMI was not recorded as the questionnaire was anonymous and these variables could not be added later.

### *Description of risk factors*

Twenty-one (40%) of those surveyed had at least one CVD risk factor, while 60% (n=32) had no cardiovascular disease risk factor (Fig. 1). Of the 53 patients, 28% (n=15) had a family history of CVD, 9% (n=5) had a parent/guardian with a previous diagnosis of dyslipidaemias, 8% (n=4) patients had type 1 diabetes mellitus (T1DM) and 30% (n=16) lived with someone who smoked within the home (Fig. 2).

### *Children who would fulfil screening guidelines as per 2011 NHLBI guidelines:*

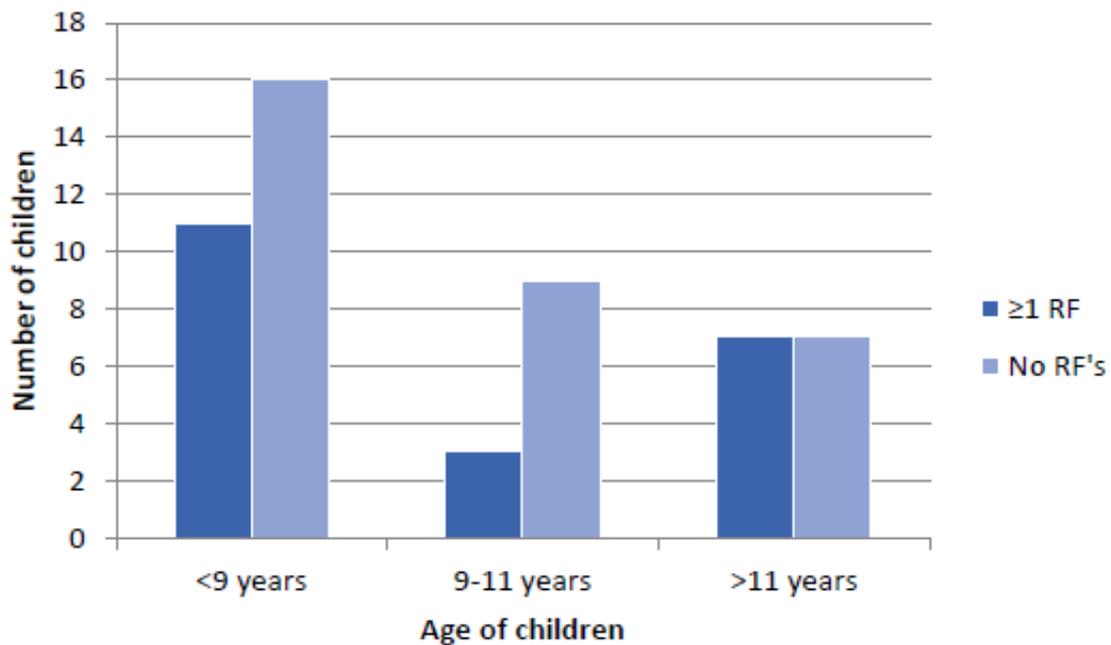
Eleven (40%; n= 11/27) of patients below the age of 9 years fulfilled the criteria for screening. All children between the ages of 9-11years (n= 12/12) were recommended for screening based on age as per 2011 NHLBI guidelines, while 25% (n= 3/12) of the children aged 9-11 years fulfilled the criteria for targeted screening. 50% (n= 7/14) of those aged 12 or older fulfilled the criterion for screening as per guidelines.

Overall 40% (n = 21/53) of patients surveyed met the criteria for targeted screening (11/27 aged up to 9 years, 3/12 aged 9-11 years, and 7/14 aged 12-14 years), while 53% (n= 30/53) met the criteria for screening per the 2011 NHLBI guidelines when universal screening in all patients aged 9-11 years is taken into account.

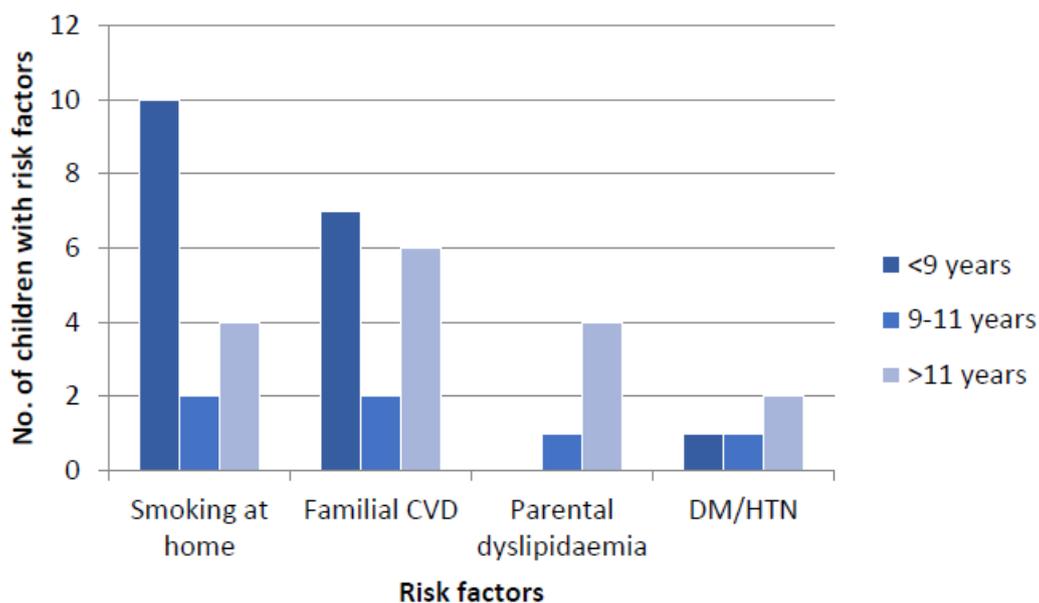
If this is restricted on the basis of age to those aged 9 and over, 100% (n=26/26) would be screened on the basis of 2011 guidelines with 38% (n=10/26) screened on the basis of targeted screening.

*Parental Attitudes to Cholesterol analysis*

Fifty-two of those surveyed (98%) had no objection to the possibility of a cholesterol analysis being performed on their child. When those surveyed were asked regarding management of lipid issues, 93% (n=49) stated they would be happy to receive advice from a dietician regarding management of dyslipidaemia. When asked regarding the possibility of cholesterol lowering medication being prescribed in the case of raised cholesterol, 58% (n=31) of parents surveyed expressed concerns such as lack of information, dietary preference and long-term medication effects (Table 1).



**Figure 1.** Number of risk factors of included patients grouped by age.



**Figure 2.** A breakdown of the risk factors identified in patients in each age range.

| <b>No. Parents</b> | <b>Primary Concern listed by parent</b>                                                   |
|--------------------|-------------------------------------------------------------------------------------------|
| 17% (n=9)          | Lack of information about statins                                                         |
| 11% (n=6)          | Prefer to exhaust dietary measures                                                        |
| 9% (n=5)           | Concerns about long term effects of statin medications being prescribed to their children |
| 4% (n=2)           | Only agreeable to statins as a last option                                                |
| 17% (n=9)          | No reason given                                                                           |

**Table 1.** Concerns from parents in relation to treating their child with a statin.

## Discussion

Lipid disorders in the paediatric population are often missed <sup>9 10</sup>, with previous research on selected screening demonstrates that as many as half of children with genetic and acquired cholesterol disorders are missed in the absence of routine screening <sup>6 11</sup>. NHLBI recommendations are aimed at providing screening to the whole paediatric population and this has not been previously studied or examined for feasibility. Our results showed that within this group 40% of children had at least one cardiovascular risk factor. This 40% met the criteria for targeted screening, and this increased to 53% when the 2011 NLHBI guidelines were applied. Additionally, further restriction to those aged 9 years and over where full population screening is advocated in the 2011 guidelines, resulted in 100% meeting the criteria for screening with only 38% meeting criteria on the basis of targeted screening. Thus, although a significant proportion of those surveyed have CVD risk factors, a large number of those surveyed would not be screened on the basis of targeted screening but would be included for screening based on the NLHBI guidelines.

Prior to the 2011 NLHBI guidelines, groups such as the American Academy of Paediatrics had guidelines which recommended screening with a fasting lipid profile for all children between 2 and 10 years old with an identified positive family history or patient risk factors <sup>12</sup>. However, in order for this type of selective screening program to work, the patients that meet screening criteria needed to be properly identified and there are no set standards for assessment of family histories, accurate blood pressure measurement and interpretation, and thus risk factor identification is in itself a difficult process to undertake. In addition, in order for any selective screening program to work, the screening criteria needs to be sensitive enough to detect affected patients. Unfortunately, for paediatric dyslipidaemias, significant evidence exists to indicate that using family history of premature CVD or cholesterol disorders as the primary factor in determining lipid screening for children misses between 30% to 60% of children with dyslipidaemias, and accurate and reliable measures of family history are not available <sup>11</sup>.

Although universal screening of all children aged 9-11 years is the current recommendation in the American guidelines, there are no plans currently to introduce this screening in Ireland. There are cost implications for any screening policy. Additionally, the logistics of providing follow-up care and the uncertainty about the use of statins in children are concerns which would have to be dealt with. Given the high prevalence of CVD in adults in Ireland, there is a rationale for further and larger studies in populations of Irish children, but, notwithstanding, clinicians should consider screening and counselling for CVD risk factors in individual children who are known to have one or more CVD risk factor, albeit with the inherent limitations of risk factor screening as previously addressed.

In our study population, 98% of the study population had no issue with lipid testing being carried out, although a proportion (19%) expressed concern that lipid analysis would require additional phlebotomy. 93% of those surveyed were willing to receive advice from a dietician regarding management of dyslipidaemia, however, over half (58%) expressed concerns at the use of medications to treat dyslipidaemia. Professional advice regarding dietary modification and introduction of exercise are the key initial elements of tackling paediatric dyslipidaemias with family-based therapy recommended in order to achieve best results<sup>8</sup>. It is encouraging that only 3/53 patients would object to a dietician consultation to initiate management of dyslipidaemia.

To our knowledge, this is the first study of its kind in Ireland and its results are important in interpreting Irish cholesterol screening practices and parental attitudes, in an international context. The study, however, is not without limitations. The sample size used was small; 66 patients with 53 questionnaires returned. We also evaluated only paediatric hospital in-patients, who are by definition currently of poor health. The responses within the questionnaire were self-reported and thus subject to recall bias. Although the questionnaire contained a section for height and weight, the reporting of these in the questionnaires was so low (<50%) that BMI could not be calculated. The study was questionnaire-based, and thus although parental concerns to screening were examined, a more comprehensive qualitative study would be required to fully appreciate parental expectations and concerns within this area. However, despite these limitations this study gives valuable insight into the potential and drawbacks associated with adoption of universal screening within an Irish context.

Overall, dyslipidaemias are common and increasing within the paediatric setting and are frequently missed with selective screening, while the identification of CVD risk factors in children can be challenging and can be missed. The results from this study show that the use of targeted screening would miss a significant proportion that would be included on the basis of universal screening. Further studies are required to evaluate if routine or indeed targeted cholesterol screening may be appropriate to apply to the Irish child population.

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**Ethical Approval:**

Ethical approval was obtained from the ethics committee at University Hospital Limerick, Ireland.

**Declaration of Conflicts of Interest:**

None.

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