



EAS FHSC NEWSLETTER

Issue 17
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New FHSC Article Published in *THE LANCET*

Global perspective of familial hypercholesterolaemia: a cross-sectional study from the EAS Familial Hypercholesterolaemia Studies Collaboration (FHSC).

Professor Kausik K. Ray, EAS President and FHSC Lead, introduces the paper (published 7th September 2021), the first major publication to come from the EAS FHSC, and explains the significance of its findings for patients and public health policy.



Follow link to watch this video

<https://www.eas-society.org/general/custom.asp?page=fhsc>

Full EAS press release on next page

Global EAS FHSC registry highlights the challenges of FH: late detection, undertreatment, and disparities between men and women

First data from the EAS FHSC global registry of over 42,000 individuals from 56 countries, provides a unique snapshot into the worldwide burden and challenges of FH care. Detection needs to be earlier, with greater use of intensive lipid-lowering therapy, including combination treatment, to attain guideline goals. Treatment of women also lags that of men. The findings were published on 7th September 2021 in *THE LANCET*.

FH is an inherited condition that affects about one in 300 people, more than 25 million people worldwide. Without effective lipid-lowering treatment, people with FH are at increased risk of early heart attacks, often in middle-age, due to elevated low-density lipoprotein cholesterol (LDL C) levels from birth. Early detection is essential to reduce this debilitating burden of disease and to gain decades of healthy life for people with FH.

The EAS FHSC registry was established in 2015 with the mission of empowering the global clinical community to seek change in how FH is detected and managed. According to Professor Kausik K. Ray (Imperial College London, UK), who leads the FHSC registry: "The challenges of FH were highlighted by the World Health Organization (WHO) Report on FH in 1998. However, progress in implementing the recommendations to address these challenges has been limited. First data from the FHSC provide a baseline for current FH care worldwide, critical to understanding based on 42,167 adults with heterozygous FH (53.6 percent women), shows that diagnosis of FH is usually delayed, as less than half of patients (about 40 percent) were under 40 years when detected. Among about 30,000 adults with data, the median age of FH diagnosis was 44.4 years; one in six already had heart disease at entry to the registry." Lead author, Dr Antonio J. Vallejov-Vaz, FHSC Chief Scientist (Imperial College London, UK) said: "As an inherited condition, FH is diagnosed too late, on average in the mid-40s, meaning that many years elapse before patients are identified and treatment is started. Late diagnosis also potentially misses out on opportunities to address other cardiovascular risk factors which become more prevalent with increasing age. Identification of FH must be improved to detect those affected much earlier."

Guidelines recommend that combination lipid-lowering therapy is essential to attain LDL-C goal in adults with FH. Among patients in the EAS FHSC registry on lipid-lowering therapy (59.9 percent), most were on a statin (81 percent). Few were on the highest statin doses and only about one in five were on combination lipid lowering therapy. Compared with men, women were less likely to receive the most potent statin doses or combination lipid lowering therapy, despite having higher LDL-C levels from age 50 years. Overall, less than 3 percent of patients on treatment attained LDL-C levels <1.8 mmol/L (<70 mg/dL), less so among women than men.

This FHSC report reinforces the value of early family screening for FH when a person is diagnosed with this condition (index case). Compared with index FH cases, individuals identified by screening were younger, had lower untreated LDL-C levels (by about 1.55 mmol/L or 60 mg/dL), and were less likely to have other cardiovascular risk factors such as high blood pressure or diabetes, or clinical coronary artery disease. Renewed efforts for public health policy for screening for FH is crucial to overcome missed opportunities to identify affected family members and initiate lipid-lowering therapy early.

Professor Kausik K. Ray added: "Over 20 years on from the WHO report, these first data from the global FHSC registry show that there is much to do in all world regions to improve FH care. Action is also needed to correct disparities in treatment between men and women. Findings from this unique registry are crucial for driving improvement in health policy for this common inherited condition across the globe, the mission of the FHSC."

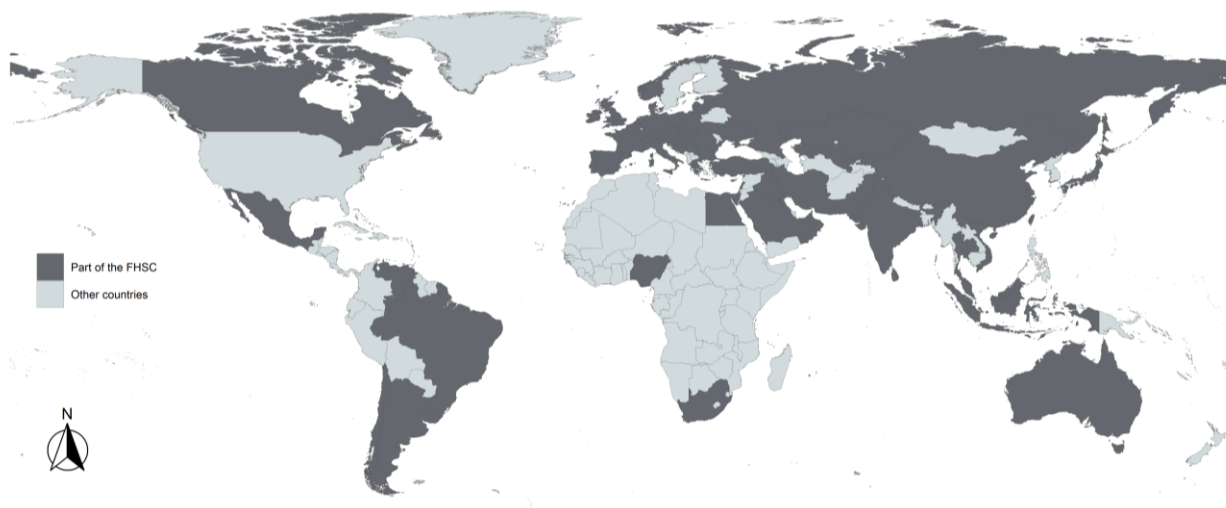
This mission underpins the EAS FHSC - FH Europe Partnership, a network of European FH patients' organisations, working together to achieve the common goal of improving FH care policy. Magdalena Daccord, Chief Executive of FH Europe said: "FH Europe welcomes this important paper from the FHSC. Together with this global FH registry, we strive to improve healthcare policy around FH, so that individuals and their families impacted by inherited high cholesterol are identified as early as possible and treated optimally. These data will drive innovation and support our advocacy efforts to prevent premature cardiovascular disease and to offer all FH patients an equal opportunity to live longer and healthier lives."

[Taken from EAS press release: <https://www.eas-society.org/news/579000/FHSC-new-publication-in-The-Lancet---highlighting-the-challenges-of-FH.htm>]

Access full article here

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)01122-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01122-3/fulltext)

The EAS FHSC now spans 67 countries (see shaded map below) and includes 80 Lead Investigators; specifically the National Lead Investigators are listed [here](#). EAS FHSC Registry includes 66,687 cases across 66 countries.



The EAS FHSC welcomes Dr. Thushara Matthias as the National Lead Investigator of Sri Lanka.

Become part of the expanding EAS FHSC

Do you have an interest in FH, collect clinical and/or genetic FH data and are keen to contribute to the **EAS FHSC Global Registry** ([CT.gov Identifier: NCT04272697](#))?

If so, we would like to hear from you!

For enquires contact info@eas-fhsc.org

More information about the EAS FHSC can be found in these open-access publications:

- [FHSC Study Protocol: 'Pooling and expanding registries of FH'](#)
- [FHSC Survey: 'Overview of the current status of FH care in over 60 countries'](#)
- [FHSC 'A global perspective on FH: Cross-sectional study from the EAS FHSC'](#)

FHSC Coordinating Centre provides a free essential web-based resource exclusive to FHSC Investigators and their local teams to support entering and managing local-level data, and sharing data with the FHSC Global Registry. Ask the Coordinating Centre for more details.

FH in the Arabian Gulf Region: Clinical results of the Gulf FH Registry

We are delighted to share the recent research article on the Gulf FH Registry published in [PLOS ONE](#).

Khalid F. Alhabib, Khalid Al-Rasadi, Turkey H. Almigbal, Mohammed A. Batais, Ibrahim Al-Zakwani, Faisal A. Al-Allaf, Khalid Al-Waili, Fahad Zadjali, Mohammad Alghamdi, Fahad Alnouri, Zuhier Awan, Abdulhalim J. Kinsaral, Ahmed AlQudaimi, Wael Almahmeed, Hani Sabbour, Mahmoud Traina, Bassam Atallah, Mohammed Al-Jarallah, Ahmad AlSarraf, Nasreen AlSayed, Haitham Amin, Hani Altaradi

Aims

Here, we aimed to estimate the prevalence and management of patients with FH in five Arabian Gulf countries (Saudi Arabia, Oman, United Arab Emirates, Kuwait, and Bahrain).

Methods

The multicentre, multinational Gulf FH registry included adults (≥ 18 years old) recruited from outpatient clinics in 14 tertiary-care centres across five Arabian Gulf countries over the last five years. The Gulf FH registry had four phases: 1- screening, 2- classification based on the Dutch Lipid Clinic Network, 3- genetic testing, and 4- follow-up.



Results

Among 34,366 screened patient records, 3713 patients had suspected FH (mean age: 49 ± 15 years; 52% women) and 306 patients had definite or probable FH. Thus, the estimated FH prevalence was 0.9% (1:112). Treatments included high-intensity statin therapy (34%), ezetimibe (10%), and proprotein convertase subtilisin/kexin type 9 inhibitors (0.4%). Targets for low-density lipoprotein cholesterol (LDL-C) and non-high-density lipoprotein cholesterol were achieved by 12% and 30%, respectively, of patients at high ASCVD risk, and by 3% and 6%, respectively, of patients at very high ASCVD risk ($p < 0.001$; for both comparisons).

Conclusions

This snap-shot study was the first to show the high estimated prevalence of FH in the Arabian Gulf region (about 3-fold the estimated prevalence worldwide), and is a "call-to-action" for further confirmation in future population studies. The small proportions of patients that achieved target LDL-C values implied that health care policies need to implement nation-wide screening, raise FH awareness, and improve management strategies for FH.

Prof. Prof. Khalid Al Rasadi (left) & Khalid F Alhabib (right)



Upcoming Technical meeting - a major milestone for FH paediatric screening in Europe



Since acceptance of the Paediatric FH Screening Best Practice to the European Commission Public Health Best Practice Portal in January 2021, FH Europe has been working to secure a high-level technical meeting (details below), gathering EU policymakers, clinical experts, and patient advocates to shed further light on this issue. It is an accompanying event of the Slovenian Presidency of the Council. It promises to be a major milestone for FH Paediatric Screening in Europe and a significant step towards applying innovation and precision medicine in prevention of premature CVD in the EU and beyond. The Slovenian paediatric FH screening model was recognised by the World Heart Federation in the Cholesterol Whitepaper in June 2021 as a possible model for FH-screening and potentially for new-born screening in general. The objectives of the technical meeting are to identify best practices in the field of FH screening and how they could be replicated and taken to scale; to assess the fundamental challenges, barriers, and opportunities to achieve equity of access to FH paediatric screening across Europe; to explore and agree next steps to ensure a systematic and comprehensive approach in Europe that leaves no-one behind.

The event has been endorsed by the World Heart Federation, the International Atherosclerosis Society, the European Atherosclerosis Society, the EAS FHSC, the Slovenian Heart Foundation, the Global Heart Hub among many others.

The official website of the meeting with the agenda and a registration link to join the debate can be found [here](https://www.nbs-fh-screening-si2021.eu/).

By FH Europe Chief Magdalena Daccord



Technical Meeting on

Achieving Equity and Innovation in Newborn Screening and in Familial Hypercholesterolaemia Paediatric Screening across Europe.

An accompanying event of the Slovenian Presidency of the Council of EU 2021.

11th October 2021
09:00 - 16:00 CET
Virtual event

For more details and to register visit <https://www.nbs-fh-screening-si2021.eu/>

