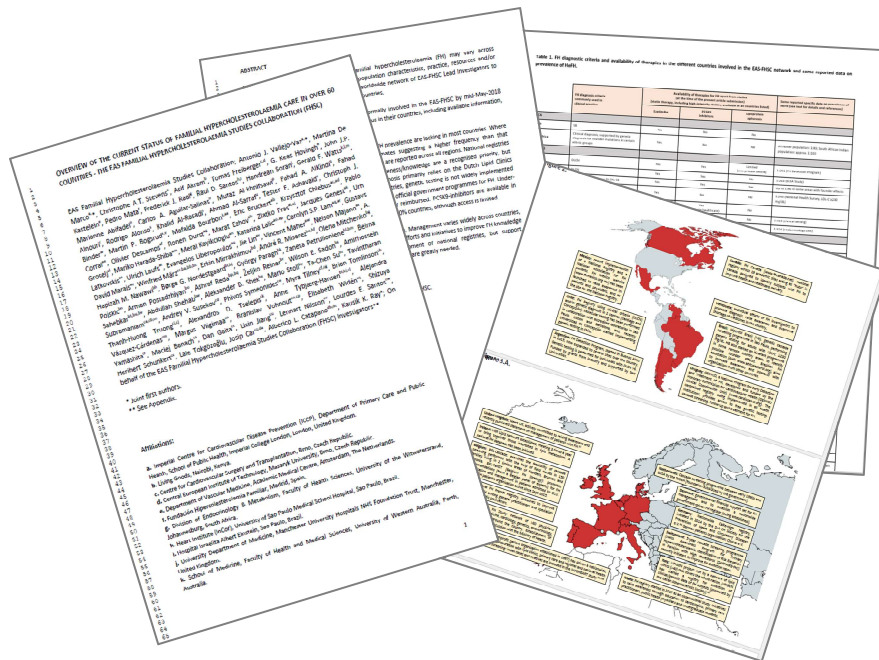# EAS FHSC NEWSLETTER

Issue 06, September 2018

From the FHSC Coordinating Centre

Article on FH care overview in FHSC countries

NEW FHSC PUBLICATION

Overview of the current status of Familial Hypercholesterolaemia care in over 60 countries - the EAS Familial Hypercholesterolaemia Studies Collaboration (FHSC)


DOI: 10.1016/j.atherosclerosis.2018.08.051

It has been a long and committing process, started in February this year and accomplished in a record time of about 6 months, but the 3rd FHSC manuscript involving all the FHSC Lead Investigators **is now available** (EAS FHSC investigators, *Atherosclerosis* Sept 2018)*,* coinciding with the 2018 FH week! This article offers the only opportunity to provide a valuable and large overview –not available so far– of the current situation and initiatives around FH across so many countries worldwide, allowing a global overview and cross-country comparison.

Number of Cases

FHSC Registry includes more than 11,000 cases

FHSC Registry – Data (Sept 2018)

Australia
South Africa (Cape Town)
Uruguay

May 2018, Lisbon
(9000 cases)
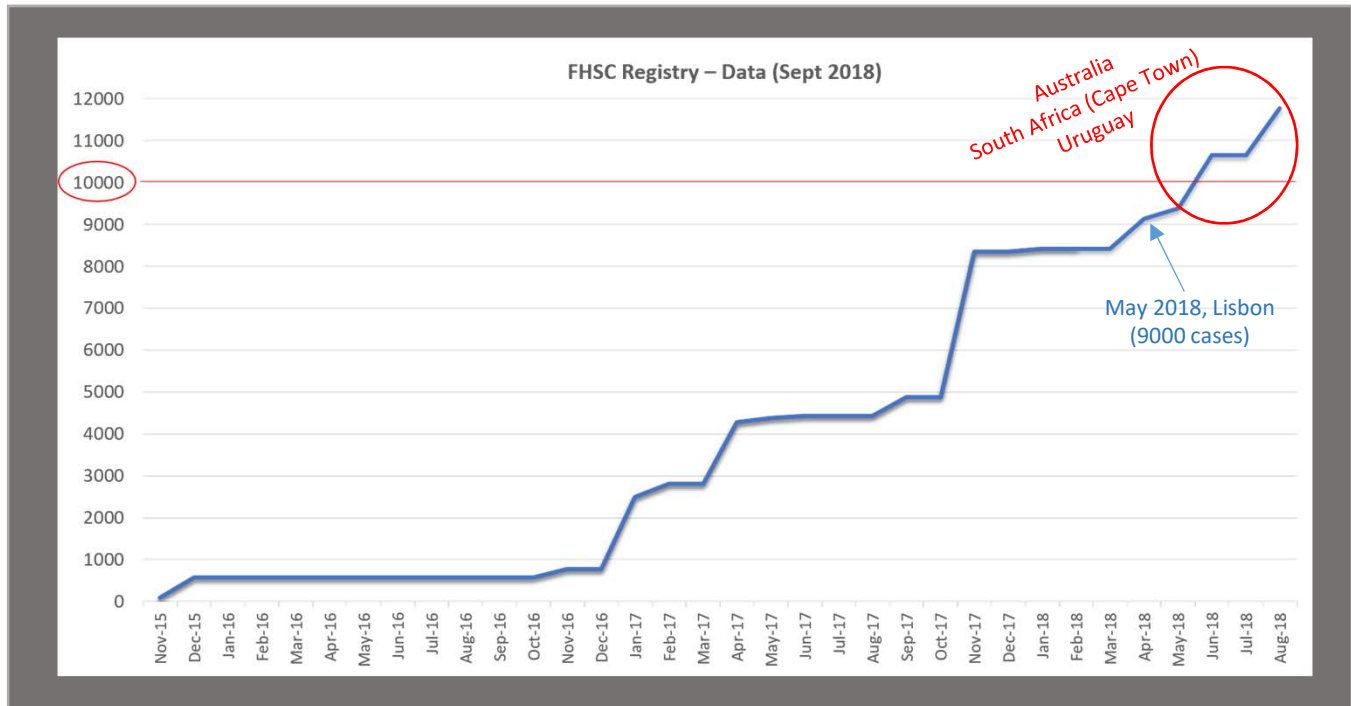
At the last FHSC Meeting in Lisbon, May 2018, we were expecting to reach the milestone of 10,000 cases included in the Registry by September. Reality has however surpassed the forecast, as owing to recent contributions from Australia, South Africa (Cape Town) and Uruguay, the Registry counts **~11,700 patients** from **25 countries** in the world. The Data will be merged into an harmonised dataset using the bespoke complex FHSC algorithm, and analyses will be conducted to study various cross-sectional relationships.

IMPORTANT

As mentioned in Lisbon, the end of this year (**December 2018**) is an important date to note in relation to data sharing. End of this year will be the cut-off date to share data for them to be analysed for inclusion in the next FHSC Results Manuscript. This article, expected to be developed in the first part of next year (2019) will be dealing with the first and novel wave of results arising from the analysis of the harmonised Registry.

Support

Uploading datasets through the FHSC Website is the most secure channel through which sharing files with the Coordinating Centre. For queries on using its functions, the new **Support** button accessible after signing in the Website, allows users to log in a request (technically named "ticket") when support on various issues is needed. There is the option to select the category of issue where help is required amongst "IT/technical", "Management" and "Data" queries, which directs the request directly to the most suitable person at the EAS FHSC Coordinating Centre. This online system is very easy to use and facilitates keeping track of the most common queries on the use of the website.

EAS FHSC Online Web Registry

Data Dictionary

The **FHSC Data Dictionary** has been completed and will be uploaded on the FHSC Website for NLIs to access and use it. The Data Dictionary is a comprehensive list of variables of interest for a Registry on FH, and serves as a guideline for not only those countries that are starting compiling their own datasets, but also to those existing registries for including potentially new variables and as an attempt to standardisation of information. Using the Data Dictionary to collect variables, with the aim of sharing with FHSC, will be of great help to harmonise the specific dataset into the FHSC Registry, as the merging algorithm is calibrated to match the standard variables on the Data Dictionary.
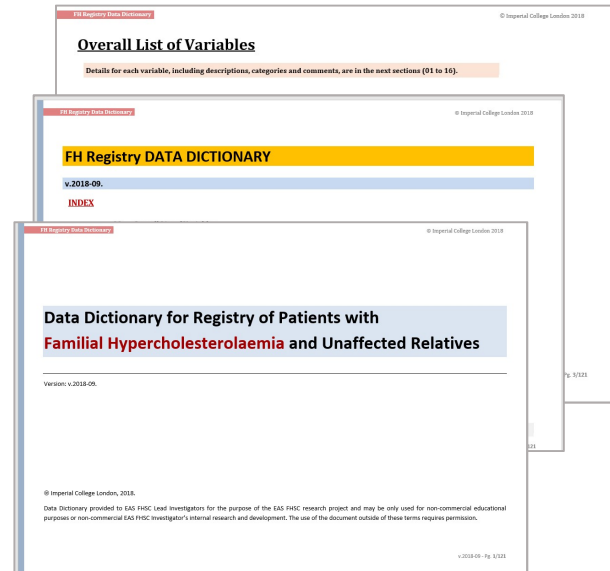
Data Entry App

FHSC is developing the individual case Data Entry App, that will be available through the FHSC Website. This App is designed for sharing data by entering patients individually, as opposed to the usual way of sharing the whole dataset files. Entering individual cases through the Data Entry App equals to build a user specific Registry within the secure FHSC servers, that will be useful where there is no pre-existing registry available, thus being used as investigator's own registry. In addition of being free to use by the NLIs, the app will allow to create a highly customisable FH Registry by e.g. choosing the variables to input, renaming the variables to their common terminology, or selecting their units of measure. Naturally, each customised registry will not be accessible by investigators others than the one creating it. The list of variables available to input comprises those shown on the Data Dictionary, which will facilitate the integration of the newly built dataset in the global registry.
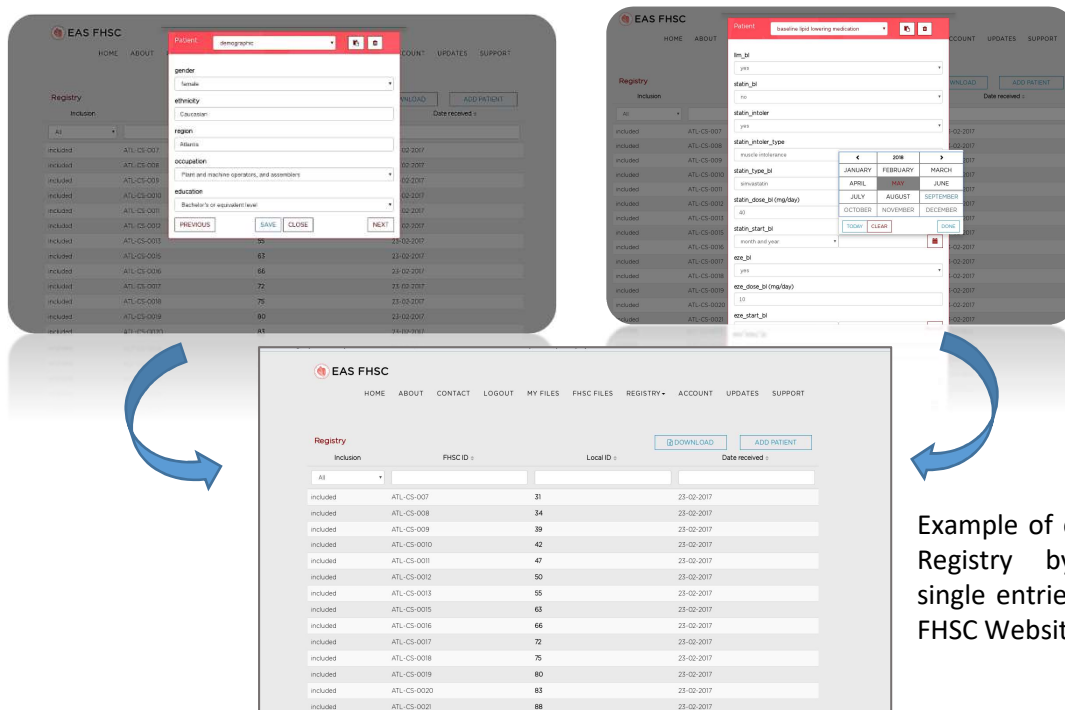
Example of custom built Registry by inputting single entries within the FHSC Website

A brief guide to pseudo-anonymisation. *By Mr Christophe Stevens, FHSC software developer*

The European General Data Protection Regulation (GDPR) is in place since May 2018. This new EU law regulates the use of personal identifiable data in Europe.

The EAS FHSC coordinating center only accepts anonymised or pseudo-anonymised patient data, thus, it is not under the burden of GDPR regulations. Conversely, any of our European collaborators in possession of personal identifiable data is under the GDPR.

UNIQUE PATIENT STUDY NUMBER
We suggest that National Investigators would create tables assigning unique patients IDs to each of their patients identifiable data. These table should never be sent to FHSC! NLIs should only share unique patient IDs and related non-identifiable data (no patient/physician/nurse/hospital names, post codes, addresses, insurance/health numbers). For example a table could look like:

UNIQUE ID	NAME	EXACT DATE OF BIRTH
1	Tin Tin	04/01/1929
2	Bat Man	27/05/1939
3	Spider Man	15/08/1962

ANONYMISATION OF DATES OF BIRTH
Date of birth and ages are different, as they are required in order to conduct statistical analyses. Our suggestion is to send dates of birth and ages indicating only months and years, but not the precise full date. As an alternative but perhaps more complicated anonymisation method, it could be possible to add a random number of days to the dates and ages.

If the table above contained real dates of birth we could add a random number of days to the real dates. In excel this can be done using = date + RANDBETWEEN(-20,20)
It is a nice feature because it allows us to be accurate for data analysis up to the chosen amount of days (here 20 days). If we were to use Year + Month only we would be accurate up to 28,29,30 or 31 days only.

UNIQUE ID	NAME	EXACT DATE OF BIRTH	RANDOM NUMBER OF DAYS	ANONYMISED DATE OF BIRTH
1	Tin Tin	04/01/1929	8	12/01/1929
2	Bat Man	27/05/1939	17	13/06/1939
3	Spider Man	15/08/1962	-13	02/08/1962

The final table shared should thus not contain any identifiable data or accurate date of birth and age.

UNIQUE ID	ANONYMISED DATE OF BIRTH
1	12/01/1929
2	13/06/1939
3	02/08/1962

Announcements

From the FHSC

NEW Blog

A blog section has been added to the FHSC Website for sharing news, comments, feedback or to simply keep in touch. The blog is still at its early stages and NLI registered on the Website will be soon able to post and comments on existing posts. One reason more to register on the website and stay in touch with the FHSC community!

FHSC Ethics Compliance

Those who have shared datasets will be asked to sign a ethics compliance disclosure form, to confirm that data collection and sharing has took place in adherence with local ethical rules and polices. This document is needed for audit purposes and for overarching project ethical approval by UK government agency.

From the EAS

FH Awareness Week

FH-week is a campaign to raise the awareness of FH with a series of daily newsletters to EAS's more than 10,000 contacts and via EAS's social media channels (Facebook ca. 3600 followers and Twitter). This year, it will take place on the week of **September 19-24**, with daily newsletter on several topics related to FH. This year's campaign will include short video interviews with National Lead Investigators, recorded during the 86th EAS Congress in Lisbon in May.

EAS Webpage and social media

Watch out for flash news and updated related to FHSC on the main EAS homepage (https://www.eas-society.org/ latest news section), with updates on the most recent events and developments of the initiative.

Atherosclerosis Special Issue on FH

In March this year, the EAS in collaboration with the journal *Atherosclerosis* has undertaken an initiative to publish a series of articles highlighting national initiatives, novel findings around FH detection, prevalence, genetic/clinical phenotypes and clinical management to be published in a special issue of Atherosclerosis. Lead Investigators were invited to contribute with manuscript that, after peer reviewing process, will be published this month in coincidence with FH awareness week.

Updated network as per September 2018

84 Lead Investigators from 69 countries

■ Committed
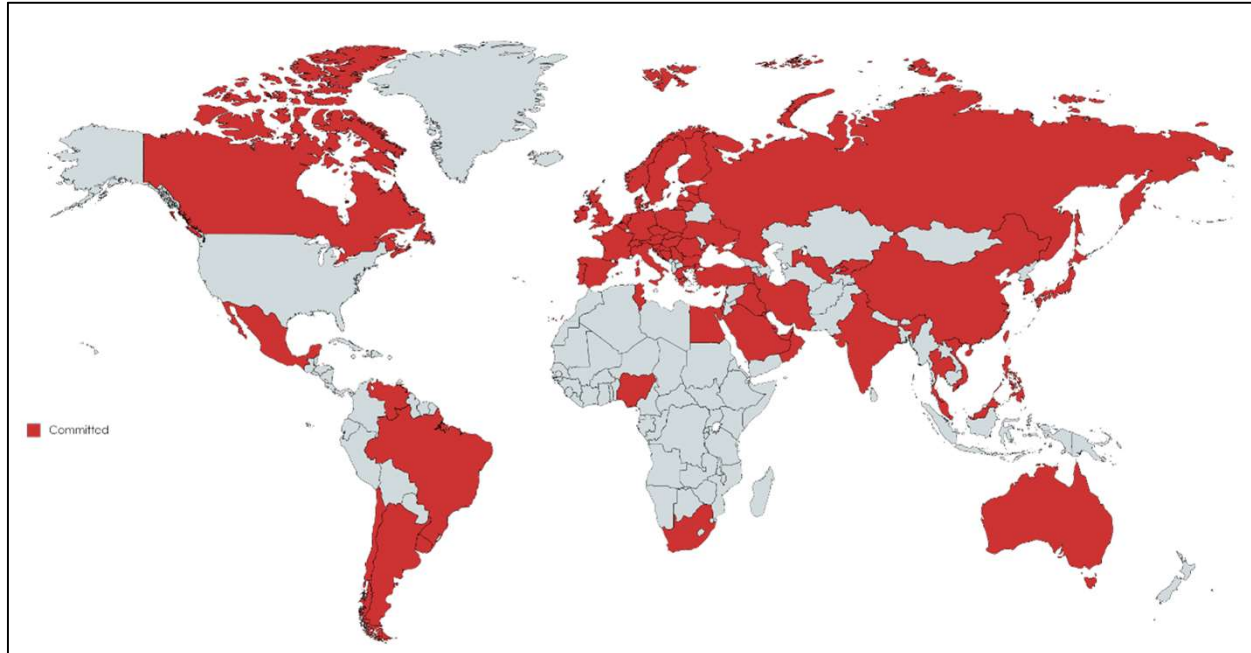
New countries and NLIs:

Welcome to:
- **Cyprus (NLI: Dr Phivos Symeonides)**
- **Thailand (NLI: Dr Weerapan Khovidhunkit)**

New Lead Investigators

Welcome to:
- **Prof Lu-Ya Wang (China)**
- **Dr Francisco Araujo Pestana (Portugal)**

Don't forget to follow the official EAS FHSC account on twitter and to use the hashtag **#fhscglobalregistry** when tweeting relevant content.

If you are interested in contributing to the next issues of the EAS FHSC Newsletters with any text, publication, events, etc. please contact us at:
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