



EAS FHSC NEWSLETTER

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www.eas-society.org/fhsc

FHSC Global Registry

Data Entry Application

FHSC Data Entry Application available

After months of developing the Individual Data Entry Application is ready to use!

The FHSC Individual Data Entry Application is a unique tool that has been designed by the technical and scientific team at the FHSC Coordinating Centre at Imperial College London for the specific use of FHSC Lead Investigators who may not have a registry in place. This Application permits the investigators the creating of their own registry by entering individual-level data (entering patients individually case by case), which can be later shared directly with the FHSC global registry.

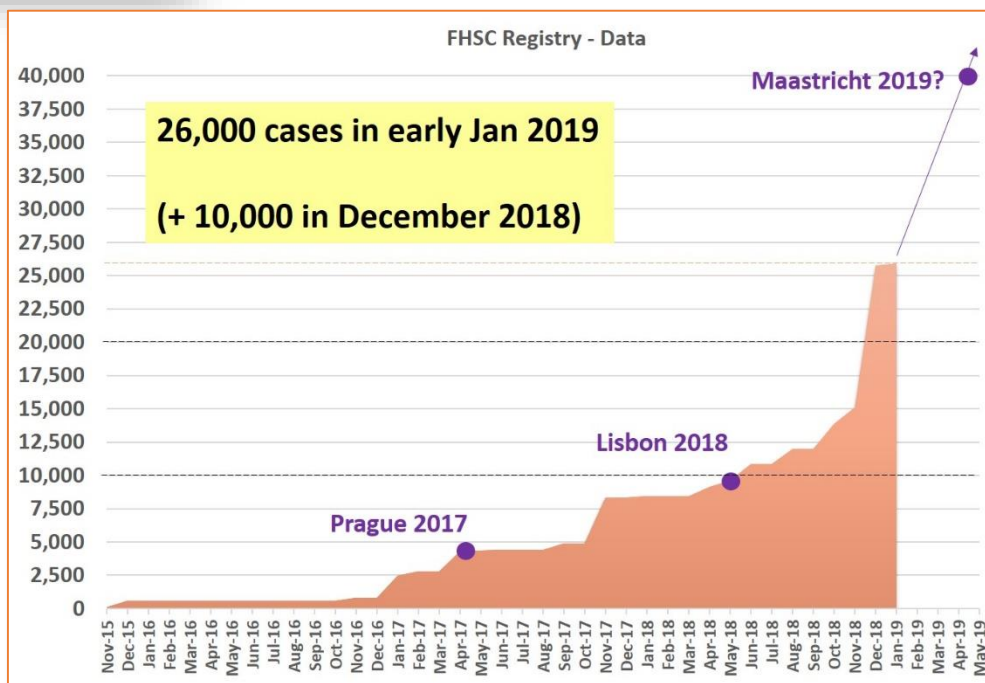
WHY TO USE THE DATA ENTRY APPLICATION:



- No pre-existing FH Registry? The Data Entry Application will allow to create a customised registry within the FHSC Servers, by choosing the variables from a pre-existing list within the Application.
- The variables in the list are already standardised following the FH Data Dictionary: as a result, the data entered through the application will be already standardised to the FHSC Global Registry facilitating data integration. One step forward to global standardisation.
- The Data Entry Application is easy to use and customisable to your variables of interest, own language and descriptions and terminology.
- The Application can be freely used by the FHSC NLI's upon registration on the FHSC Website (www.easfhsc.org)

The sharing of data as an entire unique data set (e.g. excel file) by uploading it through the FHSC Website is working as usual and a valid option.

Number of Cases



As per early January 2019, the FHSC Global Registry counts ca. **26,000 patients!**

Thanks to the progressively contribution of lead investigators and collaborators in the FHSC, the registry has now crossed the 25,000 cases included. The FHSC Registry graph is a clear indication of the potential of this exciting huge collaboration and the speed at which is developing, placing the FHSC in the way and right direction of creating a unique standard and global Registry on FH. How many patients in the world will benefit from the results of this initiative, and the new horizons the analysis of a large standard dataset will open, will depend on all of us. On the fourth year since FHSC was born, now is the time to fully dive into the project and share data. Help us to create the largest database on FH patients, to help discussion and involvement of large worldwide organisations. Where will the graph be, at the time of our next Steering Committee Meeting in Maastricht, May 2019? We are excited to find out!

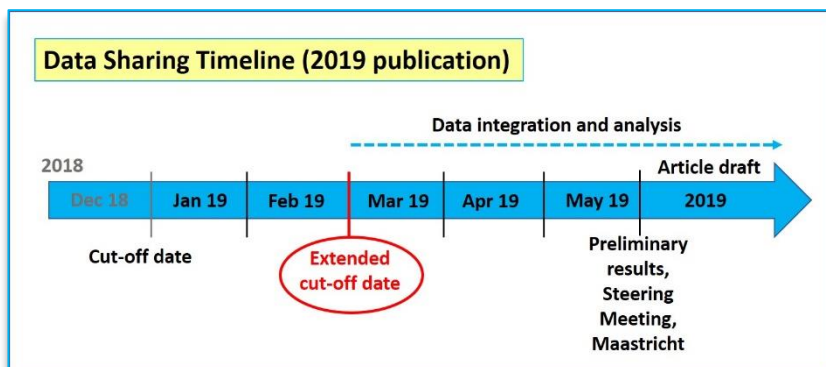
2019 FHSC RESULTS PUBLICATION: EXTENDED DEADLINE!

The availability of this large data sample will allow the scientific team at the Coordinating Centre to perform for the first time scientific analyses on the Registry. The results of these analyses will be used to produce a *publication in a high impact journal this year, 2019.*

All (and only) the NLI's contributing with their data will be listed as co-authors. As many data are still being shared as per beginning of 2019:

the absolute deadline to share data to be included in the publication has been extended to 28th February 2019.

Data shared after this deadline is not guaranteed to be included in the 2019 article, but in further ones.



FHSC Global Network

86 Lead Investigators from 70 countries**New FHSC countries and NLI:**

Welcome to:
Pakistan: Dr Fouzia Sadiq

New FHSC Lead Investigators

- Welcome to:*
- Prof Khalid Alhabib (Saudi Arabia)
 - Prof Wael Almahmeed (United Arab Emirates)

FHSC Events

SAVE THE DATE

EAS-FH Studies Collaboration Steering Committee Meeting
in conjunction with the EAS 2019 Congress in Maastricht, the Netherlands, May 26-29

Following previous years' EAS-FH Studies Collaboration Steering Committee meetings, we are currently in the stages of planning the upcoming meeting that will be held in conjunction with the 87th EAS annual Congress. The meeting will be in an updated format compared to Lisbon 2018, and will be held in Maastricht, the Netherlands, in the afternoon and evening of the last day of the EAS 2019 Congress:

Wednesday May 29, 2019, from 12:45 to ca. 22.00.

More detailed information about the meeting and on how to register will be sent to you in the next weeks. For now, please make sure to mark the dates of the Congress and the FHSC meeting in your agenda. Please note that attendance is strictly by invitation only.

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:

coordinator@eas-fhsc.org

