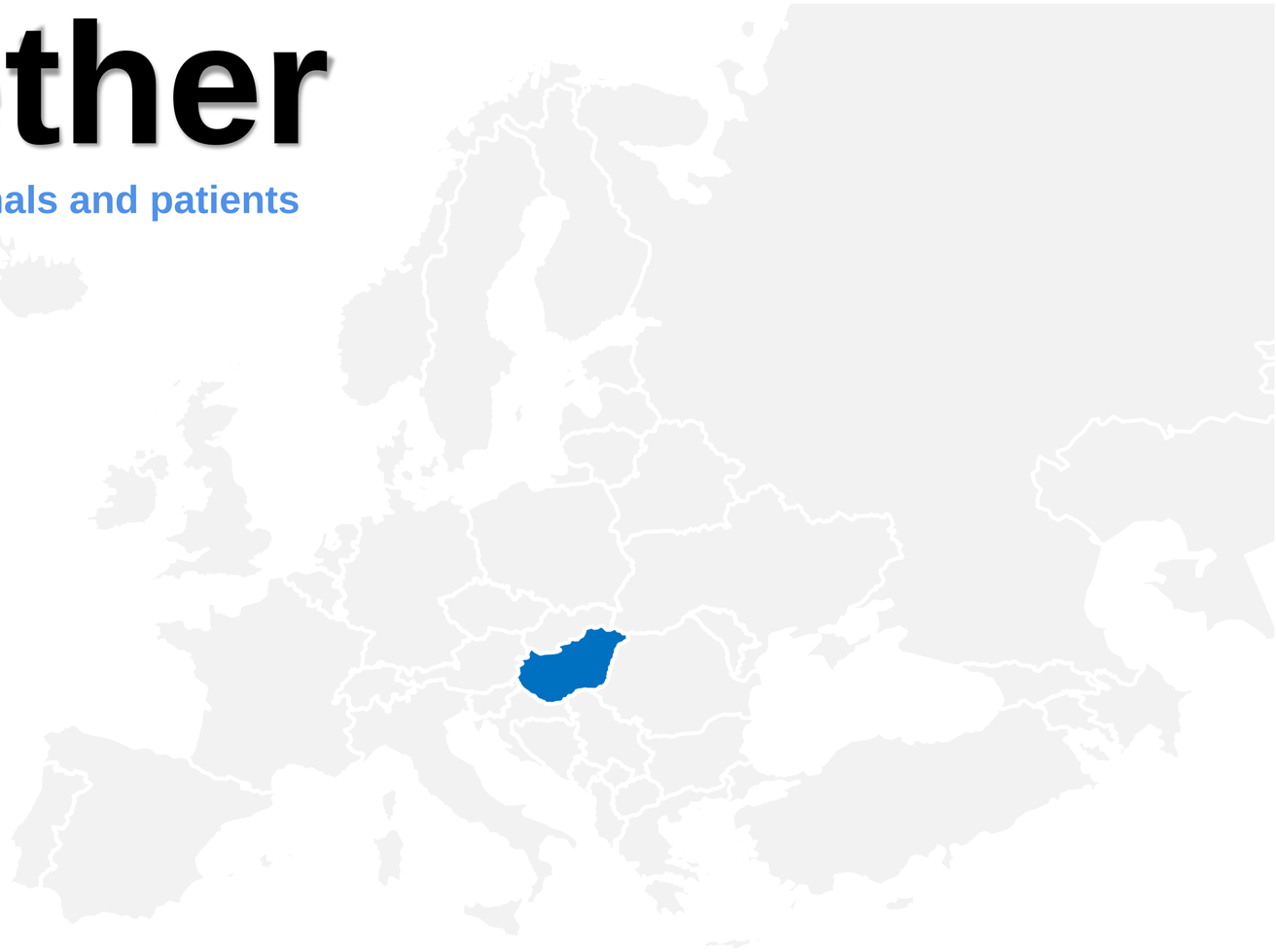
Working together

Examples of the cooperation among Healthcare professionals and patients organizations in Hungary

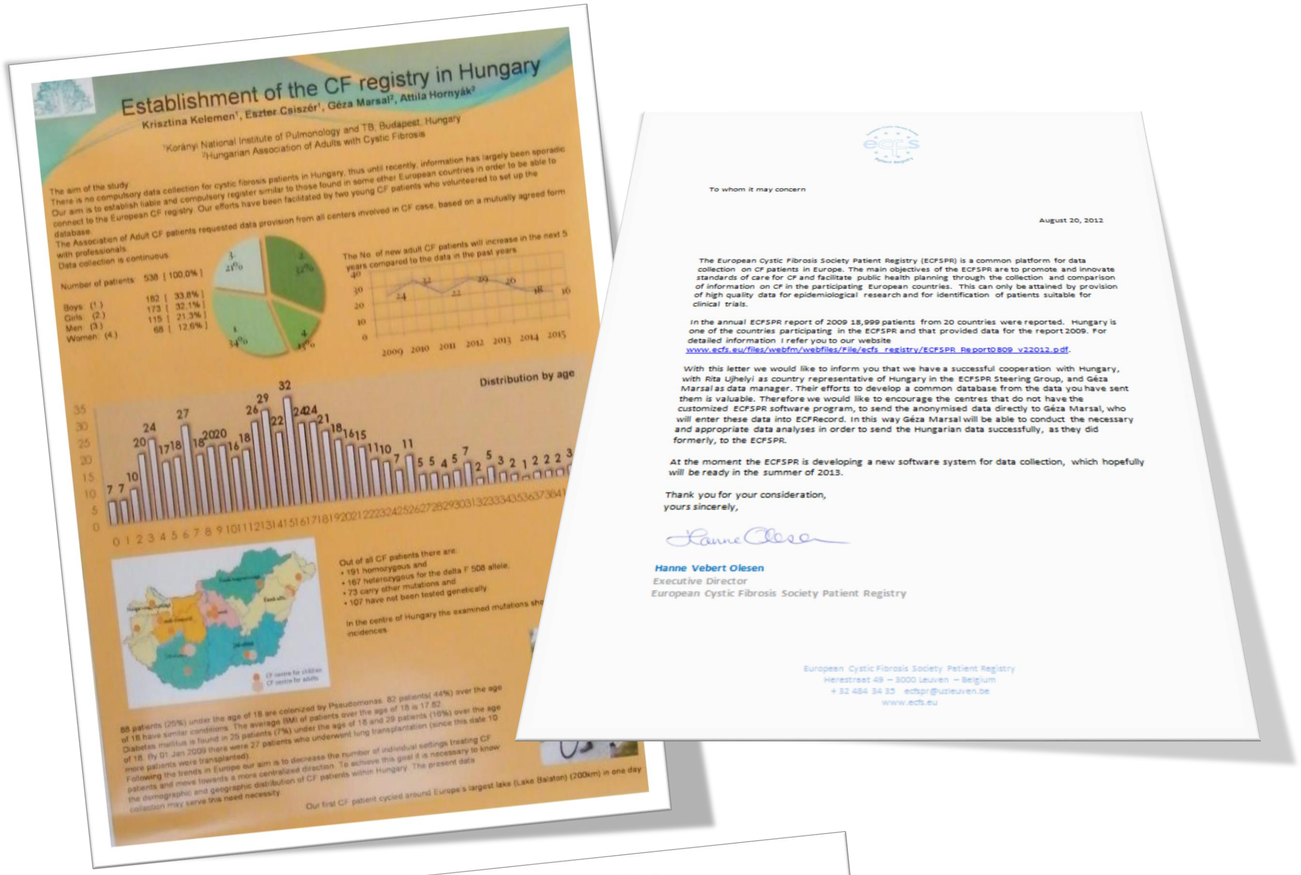


25.05.2018
Bratislava, SK

Geza Marsal
President
Hungarian Association of Cystic Fibrosis Patients

HUNGARIAN CF REGISTRY

www.cisztasfibrozis.hu



TEAMWORK

Maintained by the Hungarian Association of Cystic Fibrosis Patients, strong cooperation with CF centers and professionals

CORE TEAM

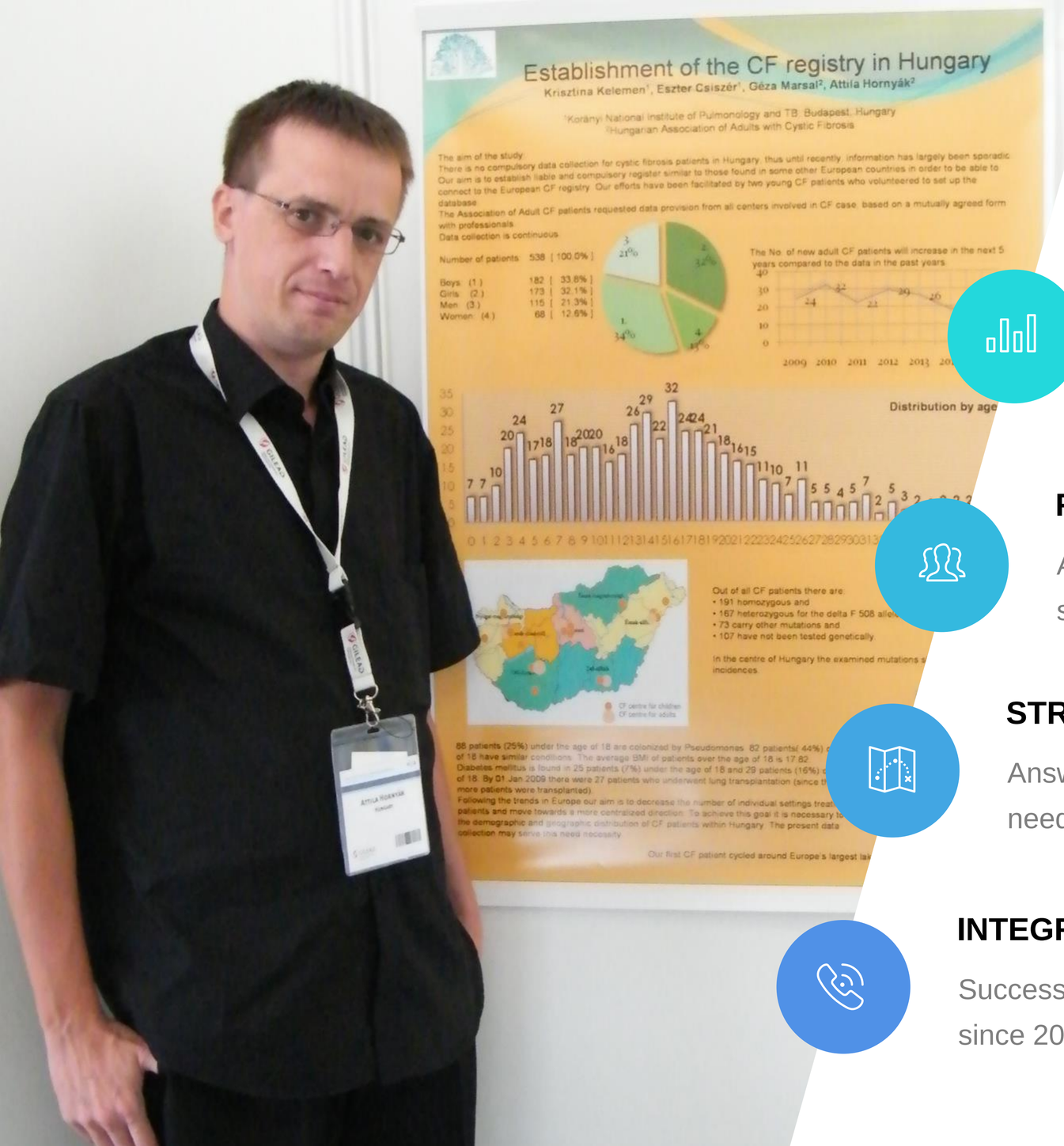
Dr. Ujhelyi Rita	country representative
Dr. Csiszér Eszter	sponsor, coordinator
Hornyák-Kovács Attila	data manager
Marsal Géza	country data manager

CERTIFICATION

Approved by the Medical Research Council (11.05.2011)

APPEREANCES

Presenting results on the annual scientific meetings and publications in HU and in EU



WHAT WE DO

Purpose of the CF registry

MEASUREMENT

Measuring, surveying, comparing aspects of CF and its treatment and providing data for the actual scientific purposes

REPRESENTATION OF INTEREST

Advocacy work through providing clear picture about the status of the Hungarian CF patients and their care

STRATEGY MAKING

Answering the current questions with facts depending of the needs of the decision makers.

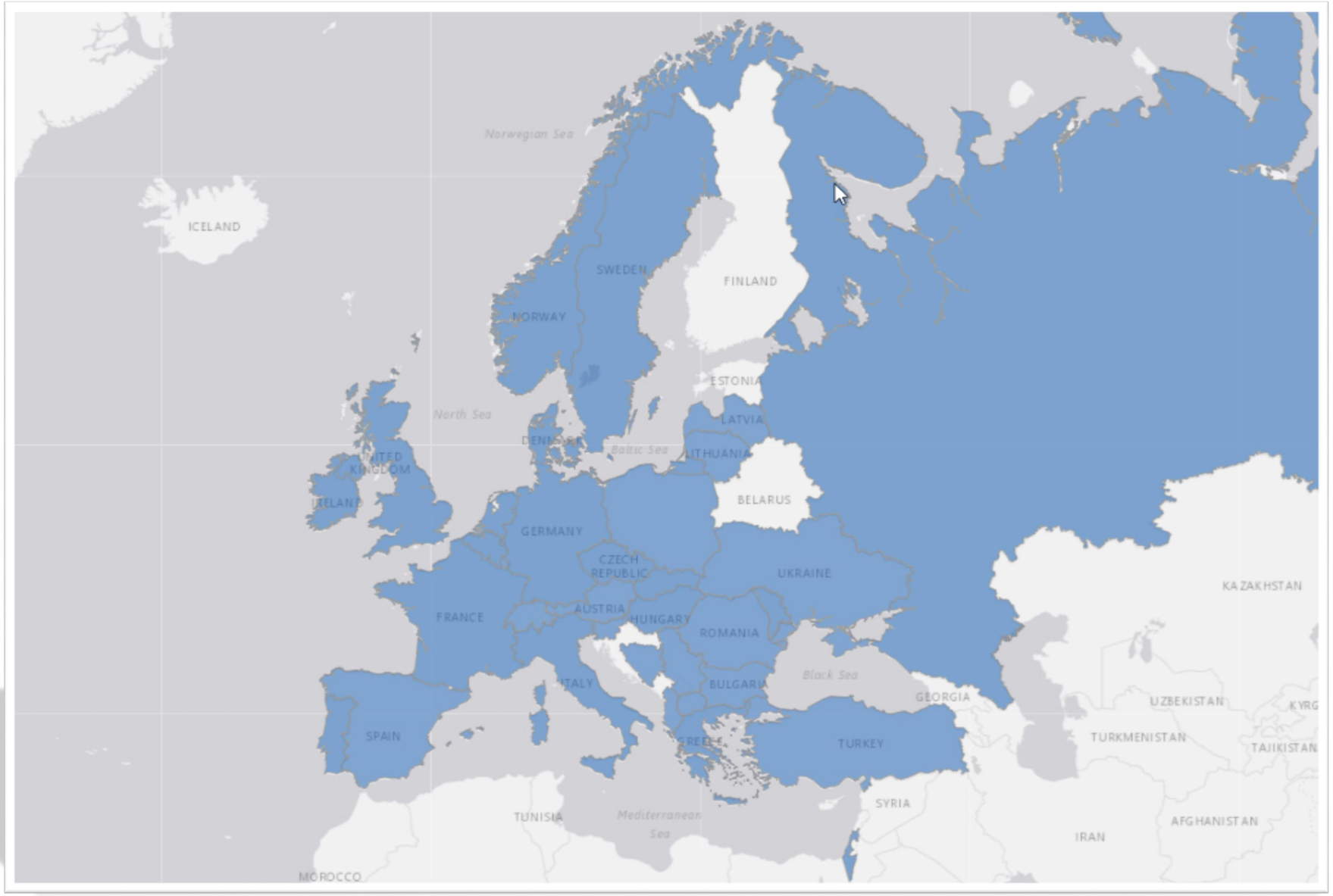
INTEGRATION

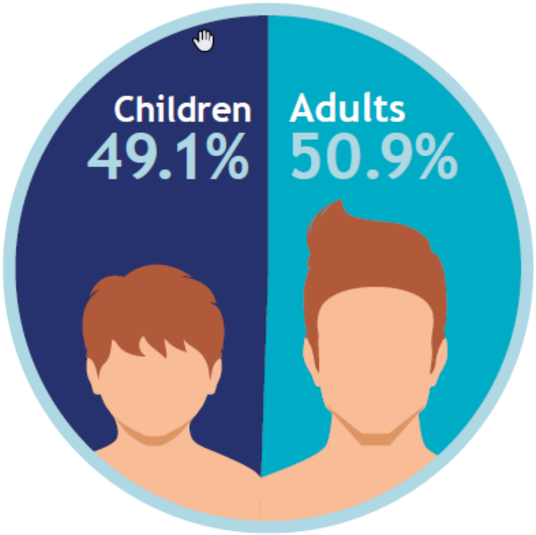
Successful collaboration with the ECFS Patients Registry since 2008

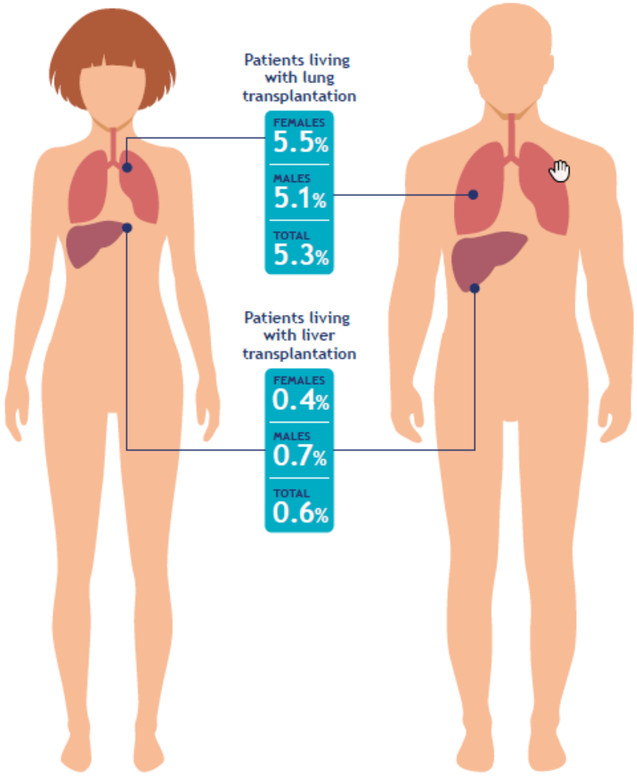
ECFS Patients Registry project

More than 42,000 people with CF

33 participating countries







History

- Hungarian Registry was established in 2007

- It was the classical story, the greatest center wanted to know how many patients were treated and what were the actual status with them

- We went through the standard evolution:
  - 1, summarize documents on paper
  - 2, create excel sheets
  - 3, MS Access (desktop) database
  - 4, centralized SQL server with reporting capabilities

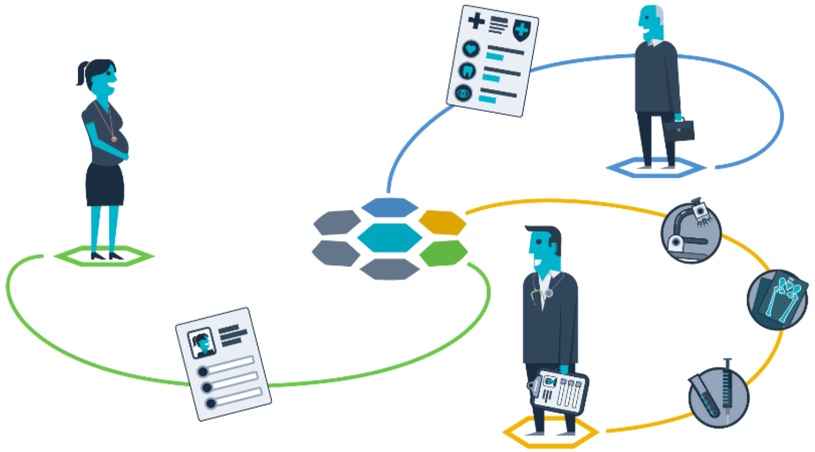
National Registry

- We have 18 (!) different locations in the country where the CF Patients are being taken care

- This means **18 different data sources** what we had to consolidate

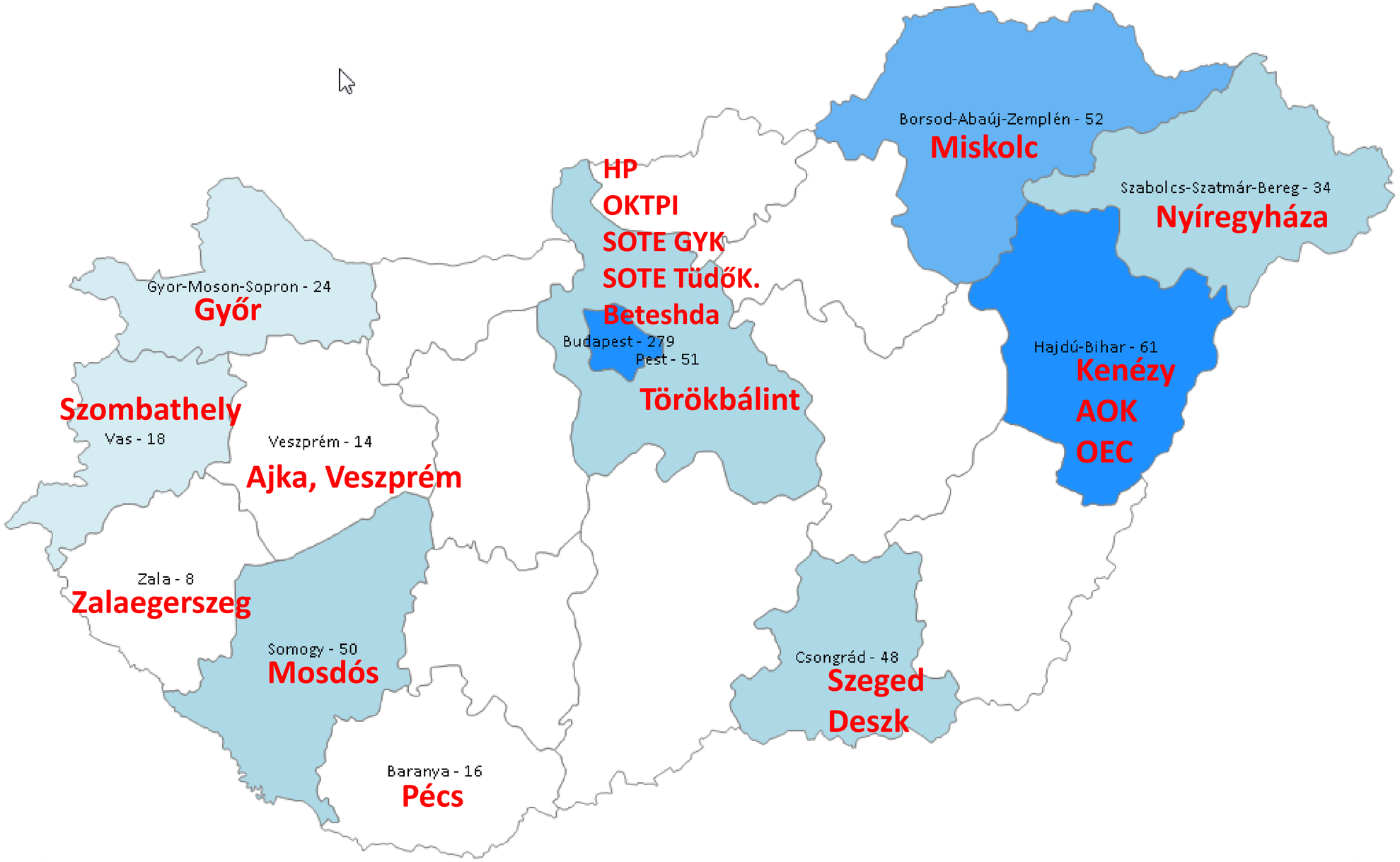
- It was obvious from the very beginning that we are not able to handle the various data sources and parameters without strong centralization

- This led the decision to create one National Registry:
  - It could show us how the patients are moving among the centers
  - It helps to avoid the duplicated patients through the centrally generated patients ID
  - It show us where are the coverages or common errors in the CF care system in HU

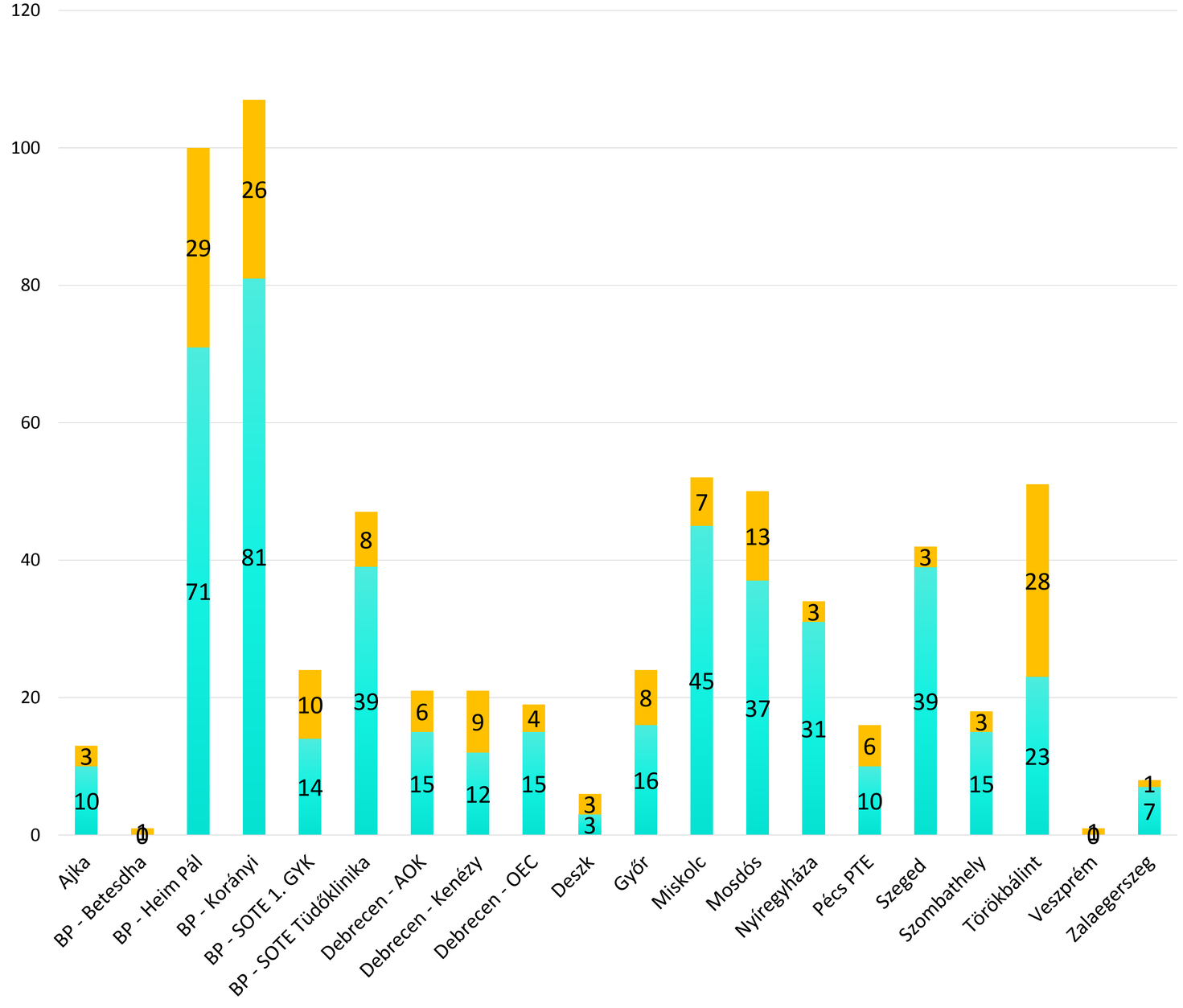


NUMBER OF PATIENTS BY CENTERS

Center names are in red



NUMBER OF PATIENTS BY CENTERS



CF CARE

There are 18 different locations in Hungary where CF care is currently avaiable

CENTERS

The biggest centers are Heim Pál Hospital (children) and Korányi Institute (adult). Both are located in Budapest

MULTICENTER PATIENTS

In some cases patients are registered at two or more centers in the same time. The reason of this is mostly the running transition from the pediatric care to the adult center or the distance of the centers

Structure

Center1

Data sent via web

Data sent via excel

Center 2

Fixing errors, creating unique IDs

Central SQL Database

Reporting services,
Custom reports, publications

Challenges

- It was very hard to proof the usefulness or its meaning **without result**
  In the first time it looked like the work what the centers invested in the data reporting it was not worth it -> resistance

- We tried to show as much as we can from the actual years data in order to show the potential of the future usage of the registry

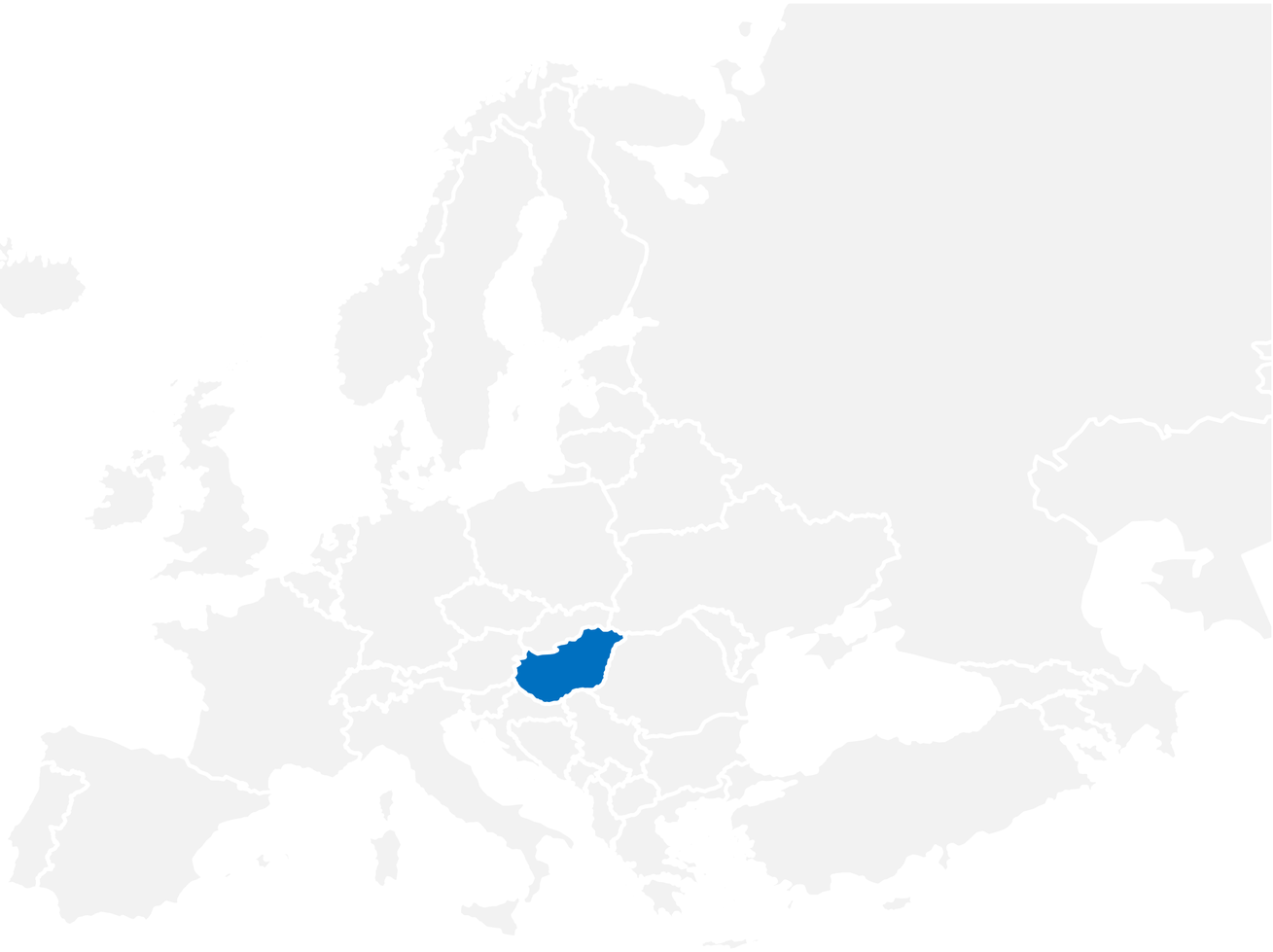
- After two years of data collecting we could provide historical data and we joined to the ECFS PR project. Joining the international community helped us to **convince all the participants** especially the resisting members

- We used our custom parameter list in the dataset but we realized we **don’t need to reinvent the hot water**:

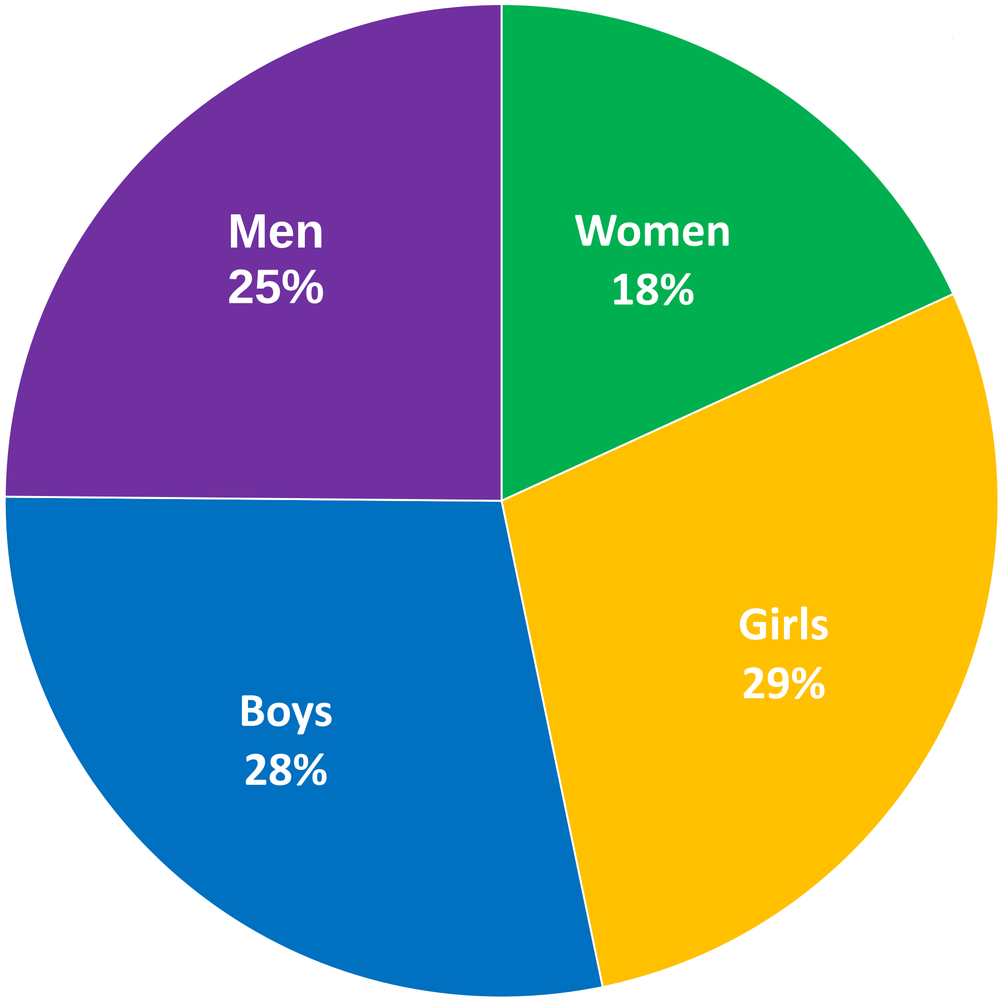
  - Implemented the ECFSPR parameter set:
  - easier data export, clear definitions, apple to apple comparison

Registry data

HU - 2015



DISTRIBUTION BY GENDER



TOTAL NUMBER OF PATIENTS: 567

Men: 302

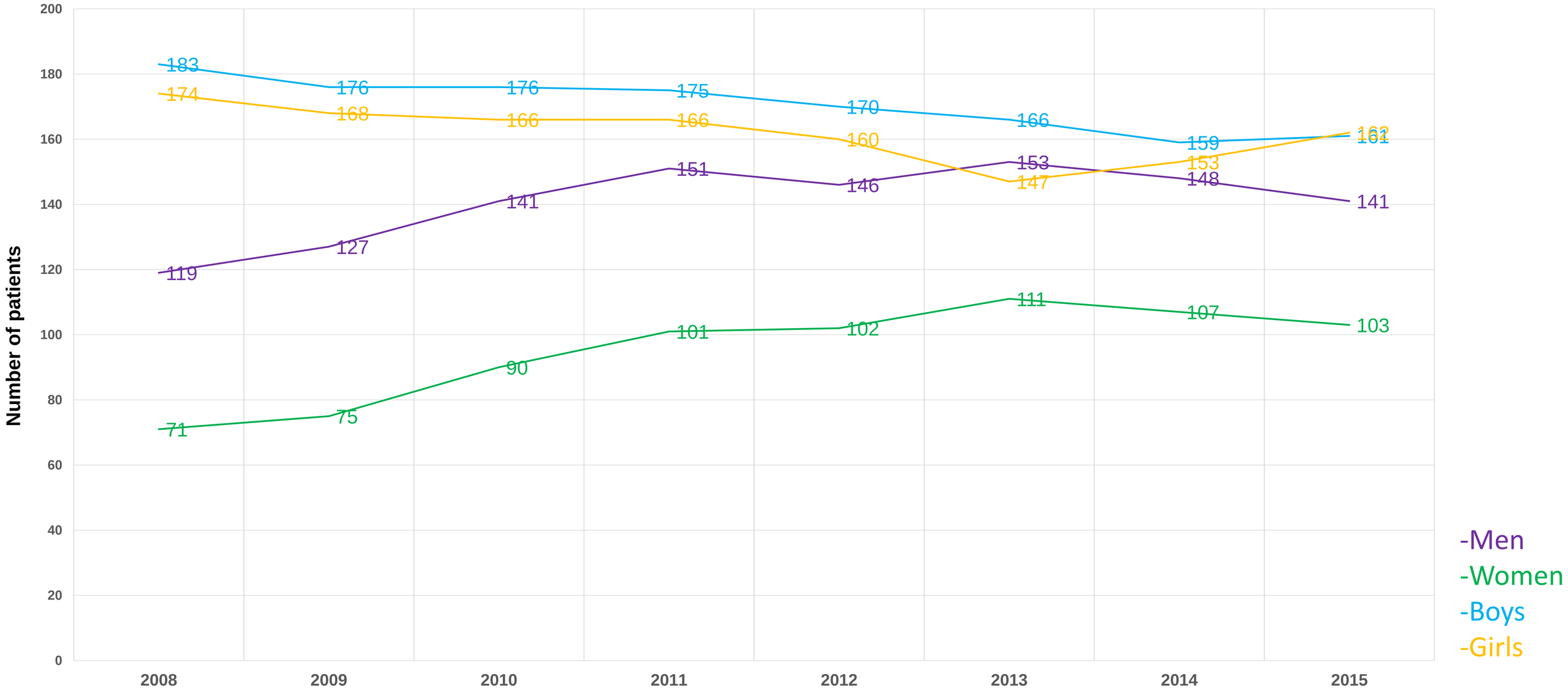
Women: 265

AVERAGE AGE

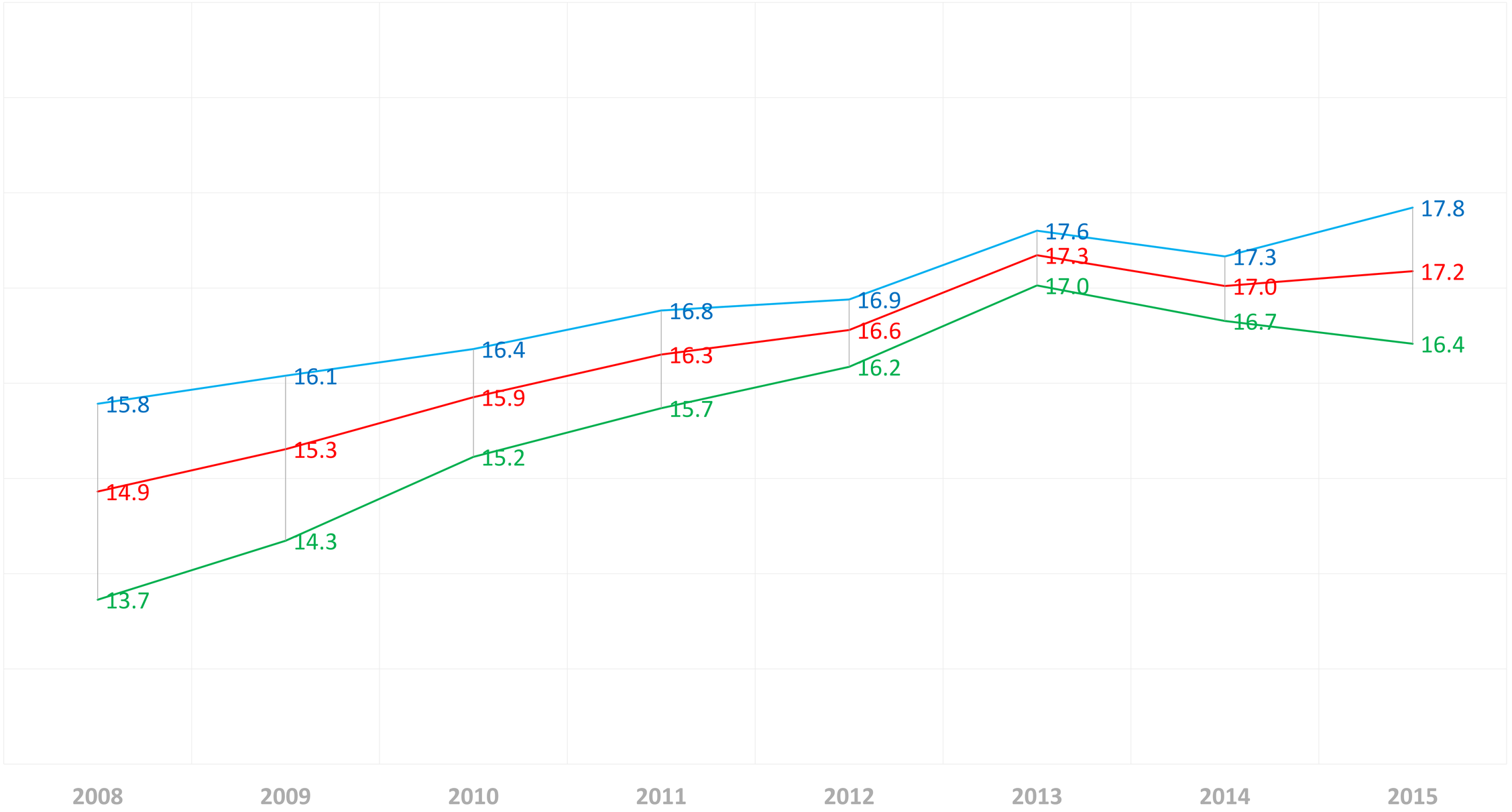
Men: 17,8 years

Women: 16,4 years

NUMBER OF PATIENTS BY GENDER



AVERAGE AGE BY GENDER



-Men
-Women
-All patients

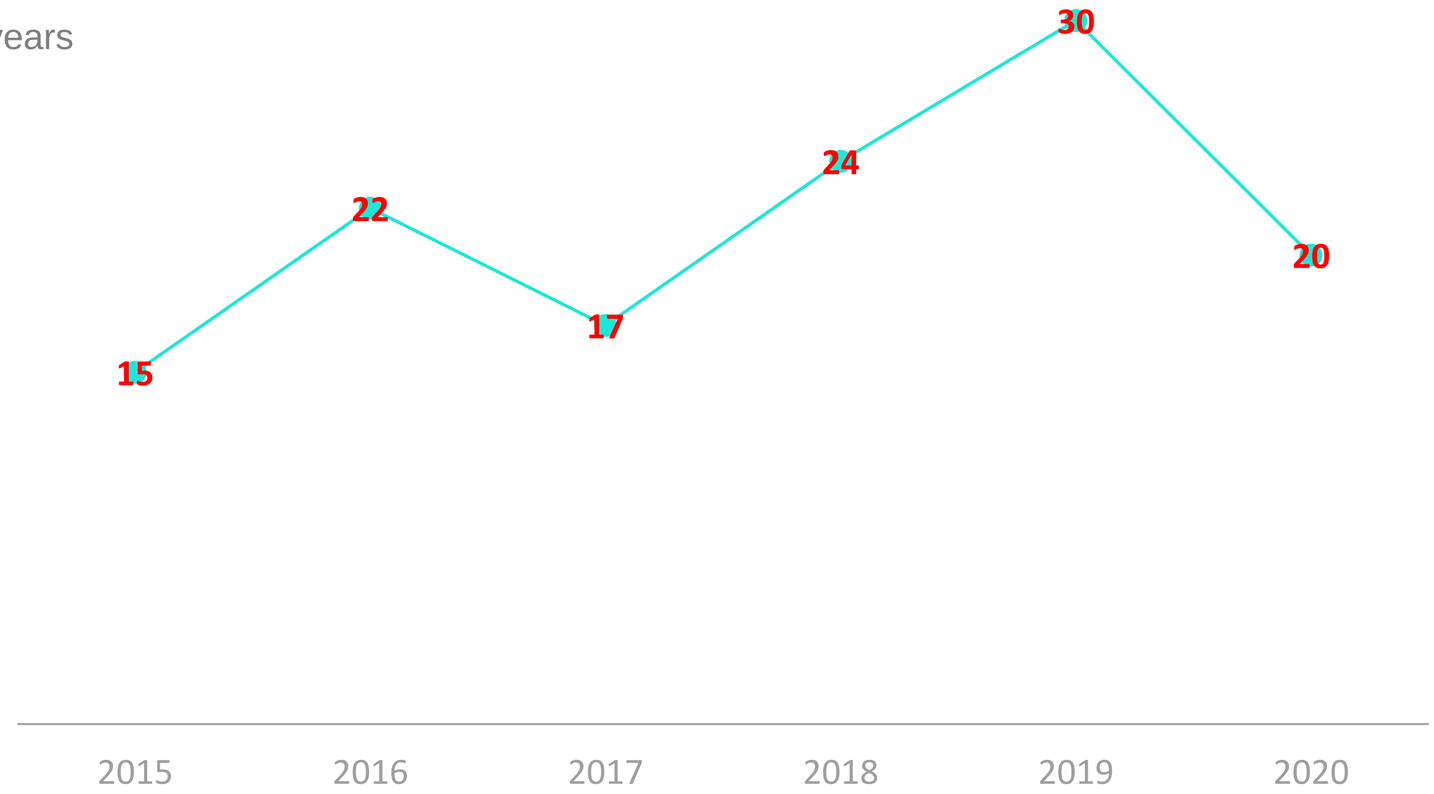
NUMBER OF PATIENTS APPROACHING AGE 18

PATIENTS TO ADULT CARE

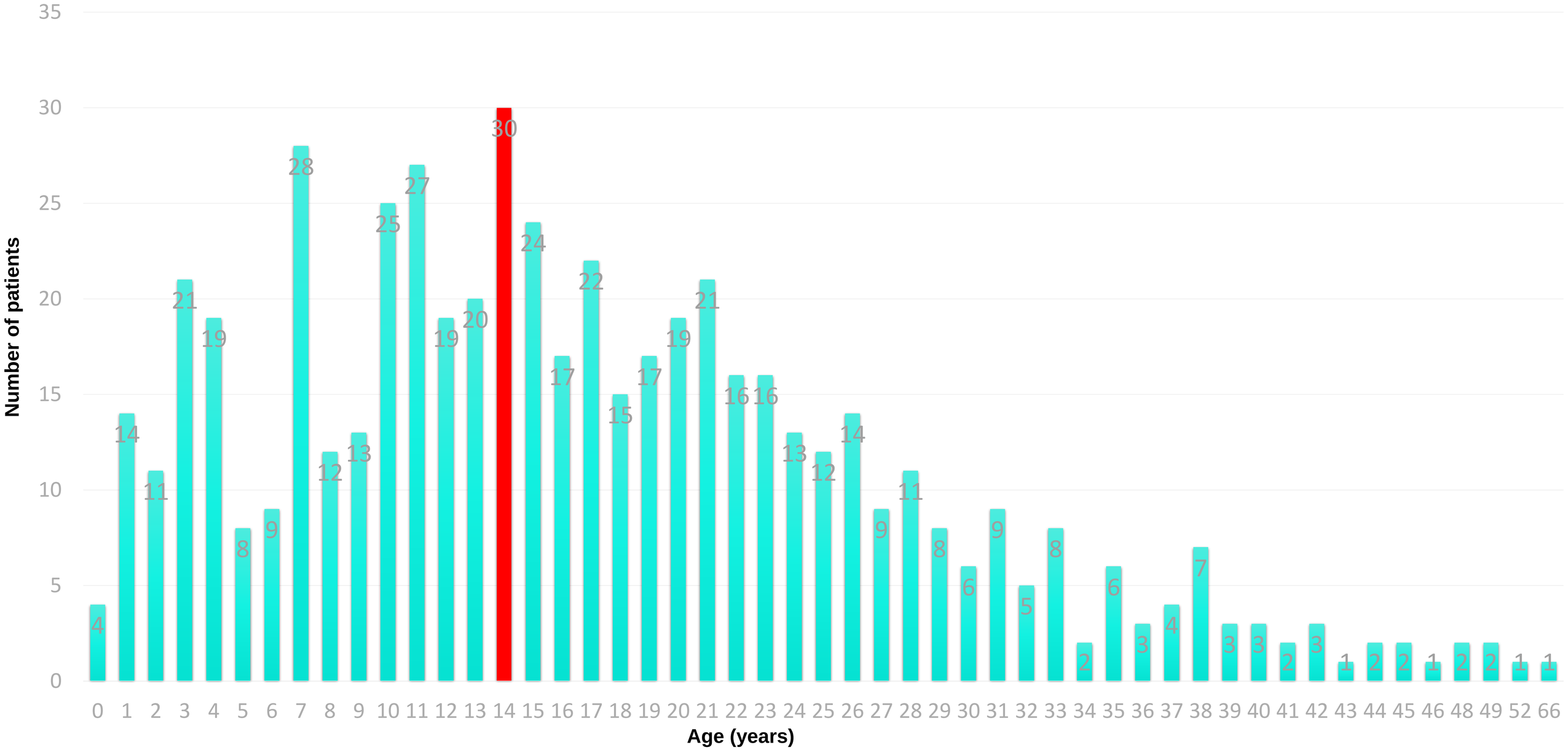
Number of patients who are going to be handled by adult centers in the following years

BY CENTERS

BP - Heim Pál	4
BP - Korányi	3
Debrecen	1
Győr	1
Miskolc	2
Mosdós	1
Szeged	4
Szombathely	2
Törökbálint	1
Zalaegerszeg	1



AGE STRUCTURE

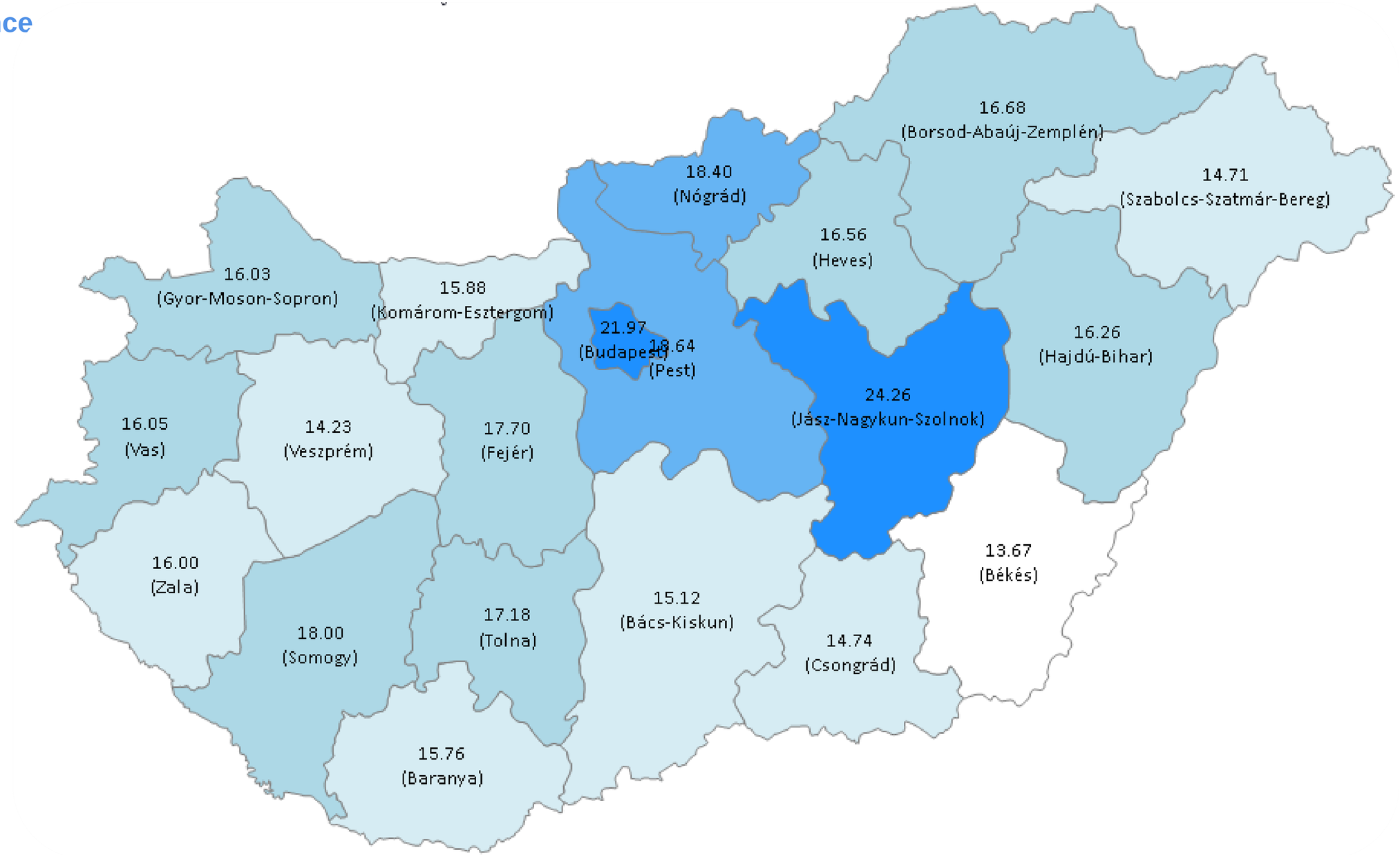


AVERAGE AGE BY COUNTIES

Average age by residence

Most / least populated counties in Hungary:

- Pest: 69
- Jász-Nagykun-Szolnok: 19
- Nógrád: 5

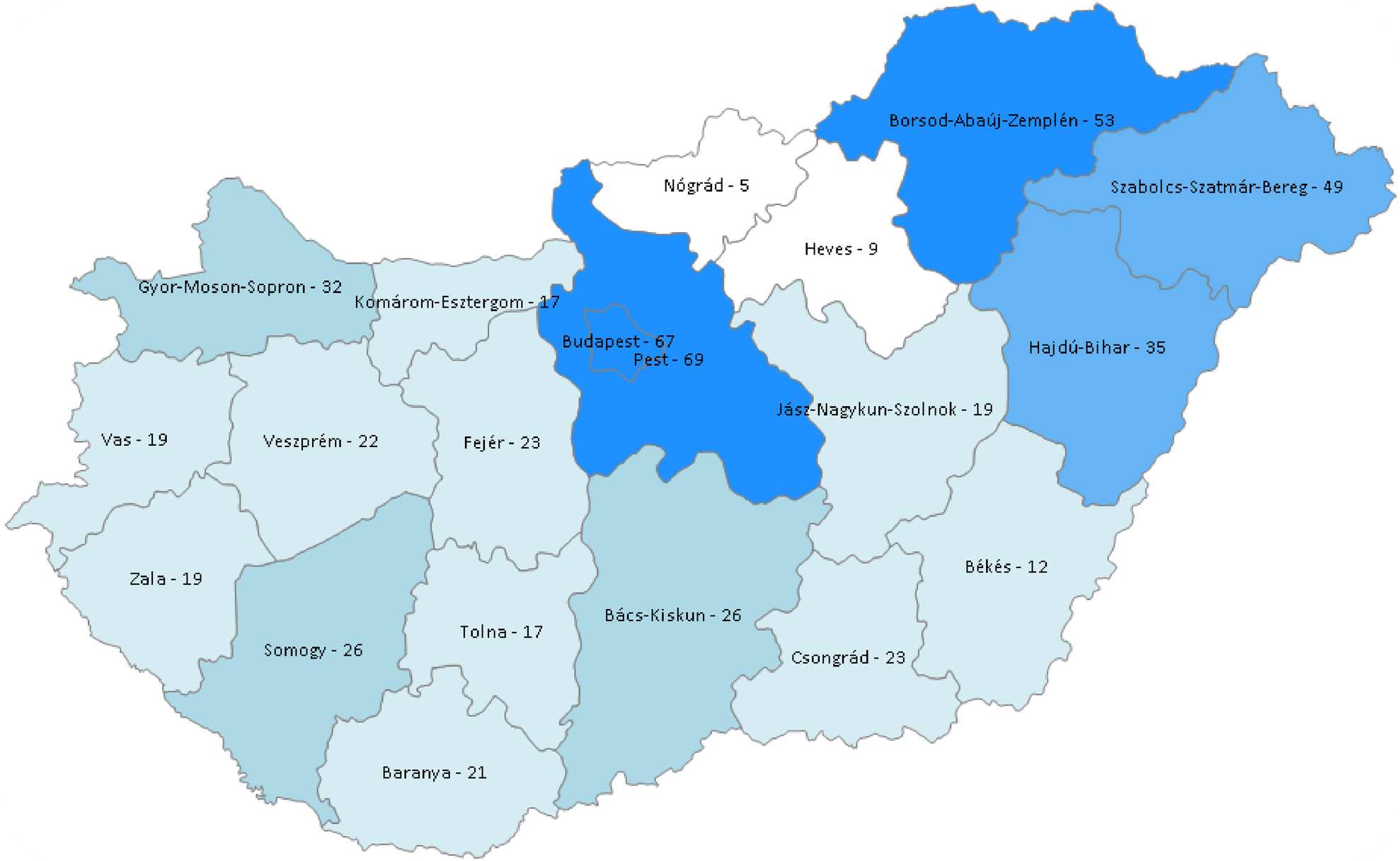


NUMBER OF PATIENTS BY COUNTIES

Numbers by residence

Average age by counties

- BAZ: 16,68
- Szabolcs: 14,71
- Hajdú-B: 16,26
- Budapest: 21,97
- Pest: 18,64



Things what we still needs to solve

- The data reporting is based on the consensus of the 18 care center, there are no regulations or instructions by the law makers or by the healthcare system / government

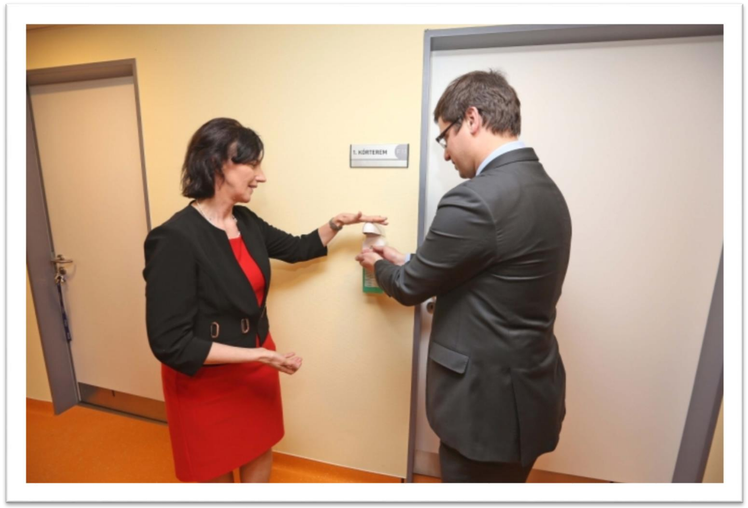
- Hungary is still working on the implementation of the neonatal screening (we have been informed about the beginning of the pilot project by the middle of 2018)

- We are working hard on the introduction of the new version of the HU registry which will be operated by the National Health Insurance Fund of Hungary and protected by the newly created legislation

- We hope we could make mandatory the reporting of the new diagnoses into the registry, based on the neonatal screening project and to harmonize the financing system according to the data from the HU registry

NATIONAL KORÁNYI INSTITUTE

REBUILT CF CENTER



Better together

COLLABORATION WITH OUR NEIGHBORS

[CONFERENCE IN HUNGARY 2017
http://www.bettertogether.hu I FIRST ANNOUNCEMENT]

DEAR FRIENDS AND COLLEAGUES!

On behalf of The Hungarian Association of Cystic Fibrosis Adults, it is a great pleasure to invite the representatives of the following countries, who are involved in the care of patients (children and adults) and/or delegates of organizations of patients and parents to the first CF Better together conference which will be held in Gárdony – Hungary 28 September – 01 October 2017

Albania, Bosnia-Hercegovina, Bulgaria, Croatia, Czech Republic, Kosovo, Macedonia, Moldova, Montenegro, Romania, Serbia, Slovakia, Slovenia, Ukraine

Four persons from each country are invited with full board. Registration will be opened on 01. 05. 2017 till 01. 07. 2017 on the http://www.bettertogether.hu site.

AIM OF THIS MEETING At this conference, we will try to establish a new forum for the discussion of the best and most recent basic and applied science and to introduce the Hungarian practice in the care of cystic fibrosis patients and the development of the lung transplantation center in Budapest. The aim of this event is to create a new way in terms of communication and to offer an opportunity in cooperation for the invited countries. The programs will reflect these priorities and bring together both clinical teams and patients associations from the invited countries.

PROGRAMME Interactive discussions, workshops and professional exhibition are planned. Sightseeing in Budapest and visits to CF centers are also included in the program.

IMPORTANT INFORMATION Date of the meeting: evening 28. 09. 2017 – morning 01. 10. 2017 Location: Gárdony, Tópart street 17. Hungary

LANGUAGE: English Scientific topics: Care o cystic fibrosis patients, Lung transplantation cystic fibrosis, meeting with patients associatio and pharmaceutical companies.

The meeting is sponsored by the Ministry of Human Capacities of the Hungarian Government

ORGANIZING COMMITTEE
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H-1041 Budapest Szigeti József u. 19.
http://www.bettertogether.hu
http://www.cisztasfibrozis.hu

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Felnőtt Cisztás Fibrózisos Betegek Egyesülete

Emberi Erőforrások Minisztériuma

KEY MESSAGES

1

TEAMWORK

Segregation of duties

2

DATA QUALITY

A chain is only as strong as its weakest link

3

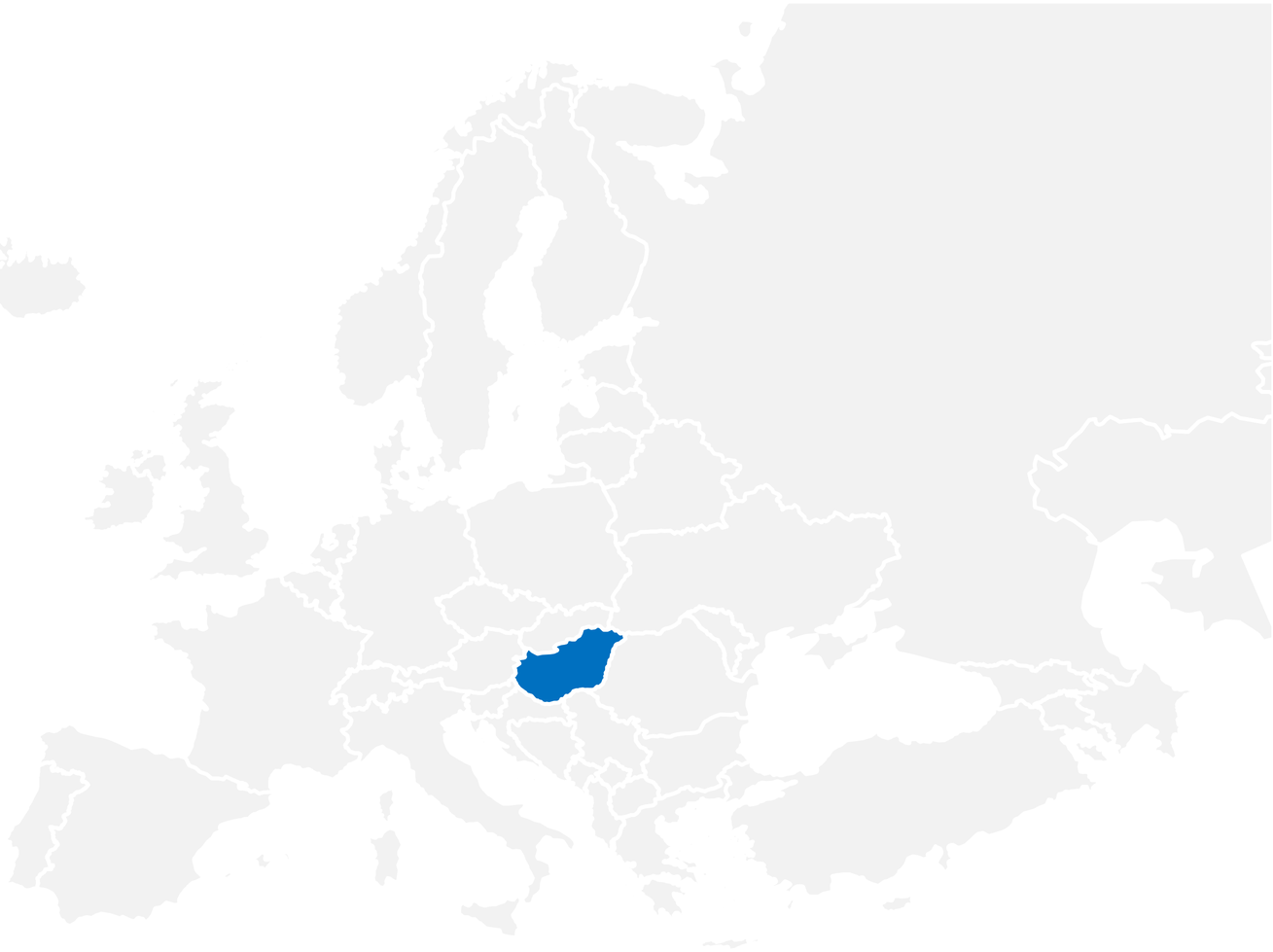
COMPARABILITY

The comparison of CF populations is essential for the development of standards for clinical practice

4

TRUST

The aim of the registry is to encourage the development instead to initiate meaningless criticism

Thank you for your attention!

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