Kidney transplantation registry program in Mashhad University of Medical Sciences: Design and rationale

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Why we need Kidney transplantation registry?

- Although recently many advances are developed in management and treatment of Kidney transplantation patients, the short and long term survival of them are far from ideal.

L. Plotnicki et al. Transplantation Proceedings, 45, 1414–1417 (2013)

- For achieving the better outcome in this ground, researchers need intense collaborative clinical researches to improve their knowledge for better management of the issues that can not be gained by single center studies.

Why we need our national registry?

- There are many prospective observational studies, clinical trials in Europe and North America, but we can’t use them totally due to difference in ethnicity, treatment protocols and health care systems.

Langer RM et al. Transplant Proc. 2012;44:2130.

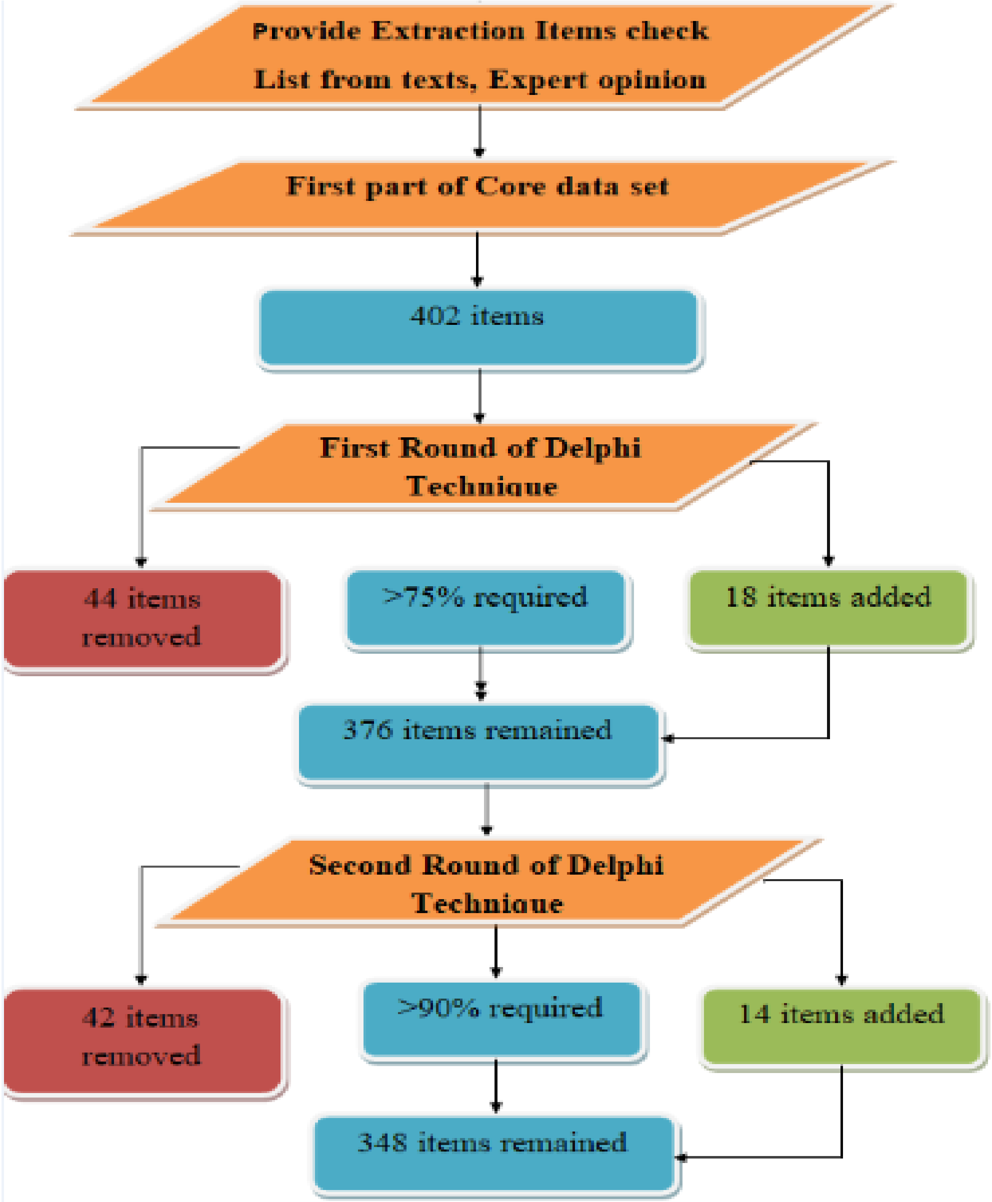
- So we need our local registry program for advanced clinical researches to improve our transplantation outcome.

Our regional registry in the Great Khorasan:

- It has been conducted from 2016 in Mashhad University Medical Sciences.
- This registry is a prospective, longitudinal program, designed as a dynamic observational cohort which enrolls all transplant recipients and living donors.
- Demographic data, etiology of CKD, and patient and graft survival have been analyzed.
- The features of the registry are a flexible patient-case system that allows capturing all kidney transplant scenarios.

Methods of providing Dataset:

- The system uses detailed basic data questionnaires in combination with follow-up visits reports.
- The dataset is designed and established using two round Delphi method in two versions (minimum and extended data), followed by a detailed data dictionary.
- Every decision has been made by a group of panelists specialized in nephrology and urology .



Provide Extraction Items check List from texts, Expert opinion

First part of Core data set

402 items

First Round of Delphi Technique

44 items removed

>75% required

18 items added

376 items remained

Second Round of Delphi Technique

42 items removed

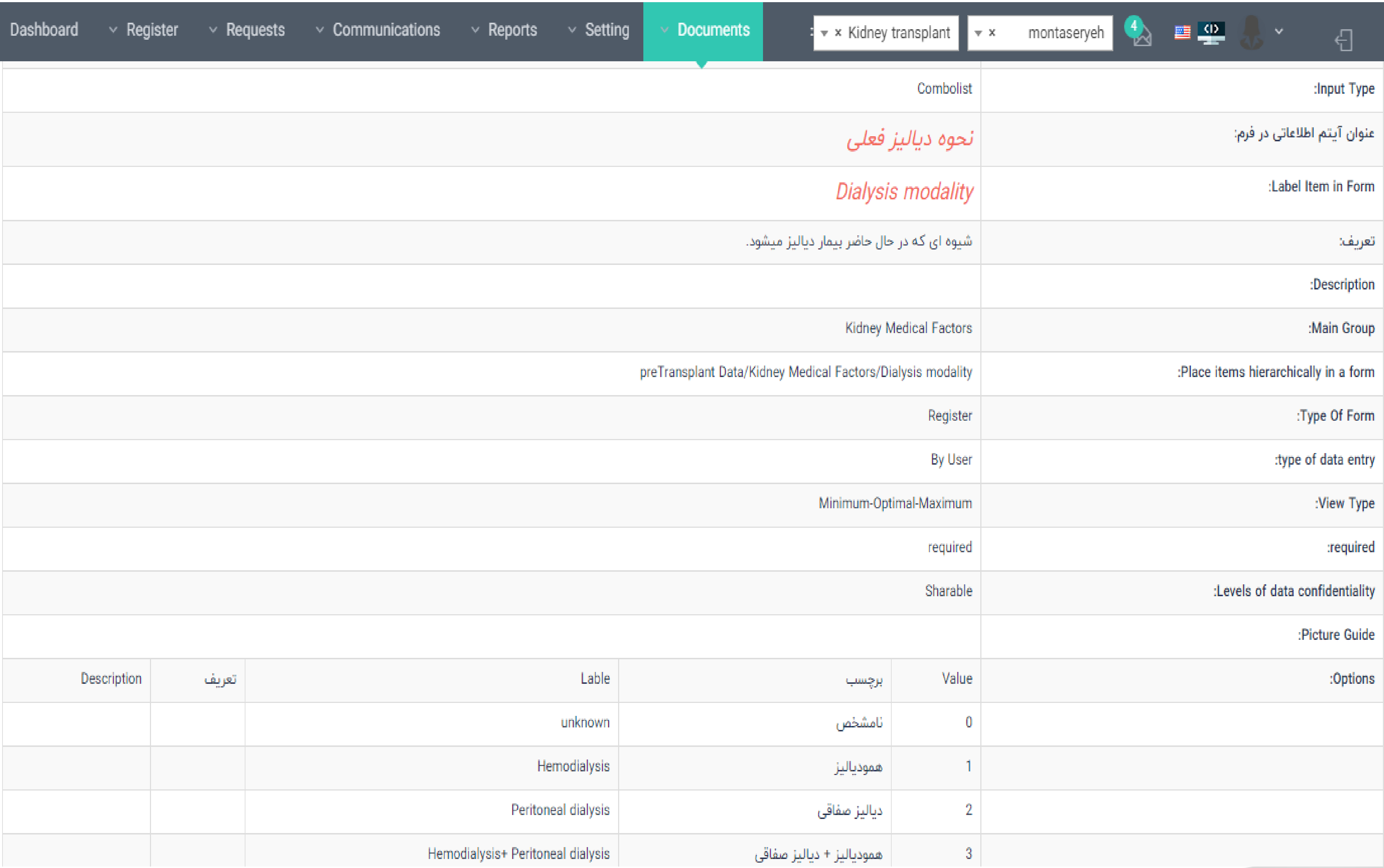
>90% required

14 items added

348 items remained

348 items remained in data set that 60 of them was accepted as minimum dataset (their fulfilling are mandatory) and 288 of them was prepared as extended data set (their completion are optional).

- Max list shows all the registry information items
- Min list shows Minimum Data Set of Registry



:Input Type	Combolist
عنوان آیتم اطلاعاتی در فرم:	نحوه دیالیز فعلی
:Label Item in Form	*Dialysis modality*
تعریف:	شیوه ای که در حال حاضر بیمار دیالیز میشود.
:Description	
:Main Group	Kidney Medical Factors
:Place items hierarchically in a form	preTransplant Data/Kidney Medical Factors/Dialysis modality
:Type Of Form	Register
:type of data entry	By User
:View Type	Minimum-Optimal-Maximum
:required	required
:Levels of data confidentiality	Sharable
:Picture Guide	
:Options	

Value	برچسب	Lable	تعریف	Description
0	نامشخص	unknown		
1	همودیالیز	Hemodialysis		
2	دیالیز صفاقی	Peritoneal dialysis		
3	همودیالیز + دیالیز صفاقی	Hemodialysis+ Peritoneal dialysis		

Data sharing protocol:

- The rules of data ownership in transplantation registry were created by strategic committee of registry that cleared the rights of ownership in stored data for publication and analysis.

1. Physicians can use public centers data after approval of system administrator and in private centers, the data can be used just only after approving of physician who is owner of the data.
2. Full data can be shared with other physicians as a team work; however the type of access and its time frame should be specified by data owner.
3. It is possible to restrict some data by owner before approving to share them.
4. Physician who is data owner can determine how often patients' information should be recorded.
5. There isn't ability to print and save Patients' data by the applicant's.
6. The program has ability to share data among all physicians in whole of Iran.

Program specifications:

- This electronic registry system is a dynamic web based system, so it is possible for users to access it without any location restriction or need to reinstallation.
- This program also can be used on tablets or mobiles and runs on all browsers.
- System is displayed in two languages (Persian and English).

Software specifications:

- Technologies used in software design consist of:

1. HTML5, CSS3, and AJAX
2. PHP5 and JQUERY as programming Languages
3. MySQL database for the data storage

Centers and Users:

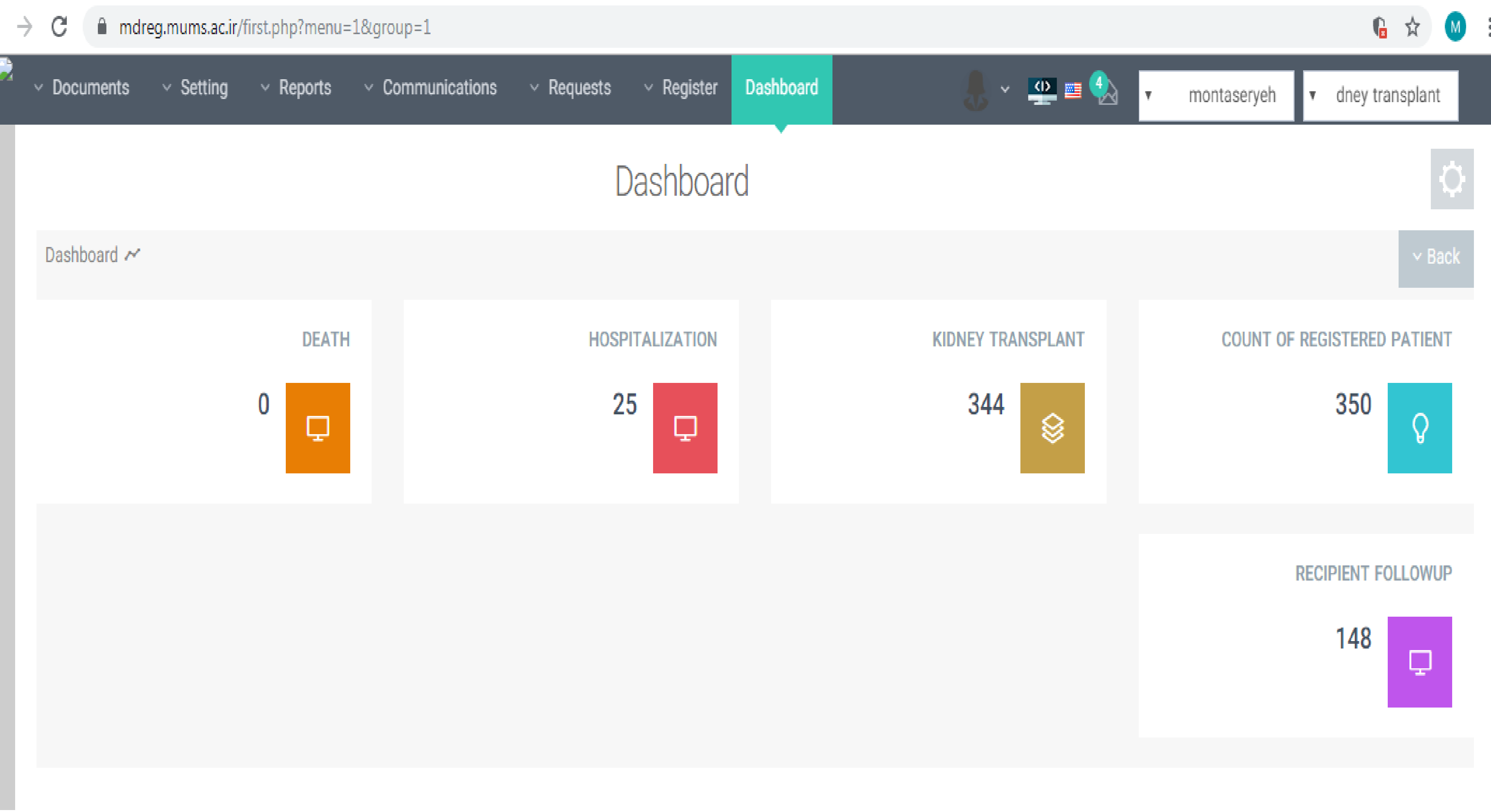
- It can be available in all medical centers, hospitals, and private clinics and offices.
- This program has 3 different access level that consist of registry admin, physicians, and data managers.

Software Output:

- It is possible to import previous patients' information to their physician database.
- Data extraction can be done in excel, xml, csv formats.
- It has capability to extract statistical reports from data as charts, graphs.
- The data is validated spontaneously over the time.

Results of our Registry:

- The data entry starts before the surgery initially, followed by after it in 1th, 3th months and every year after operation.
- Totally 344 kidney transplant recipients and 338 kidney donors consisted of 39 alive that (8) 3% were related and (31) 9 % were unrelated and 244 (71.3%) cadaveric donors were registered until now.

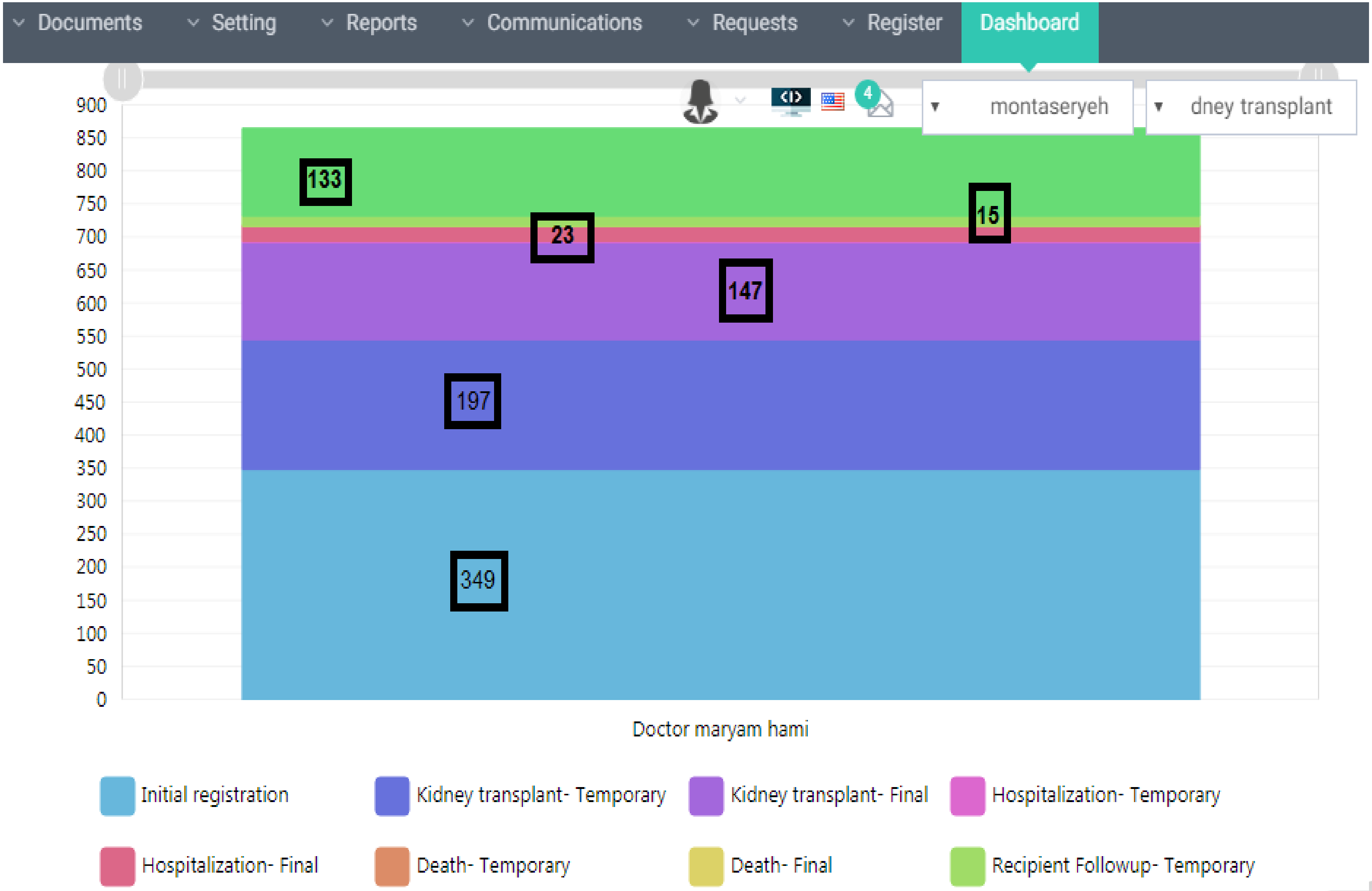


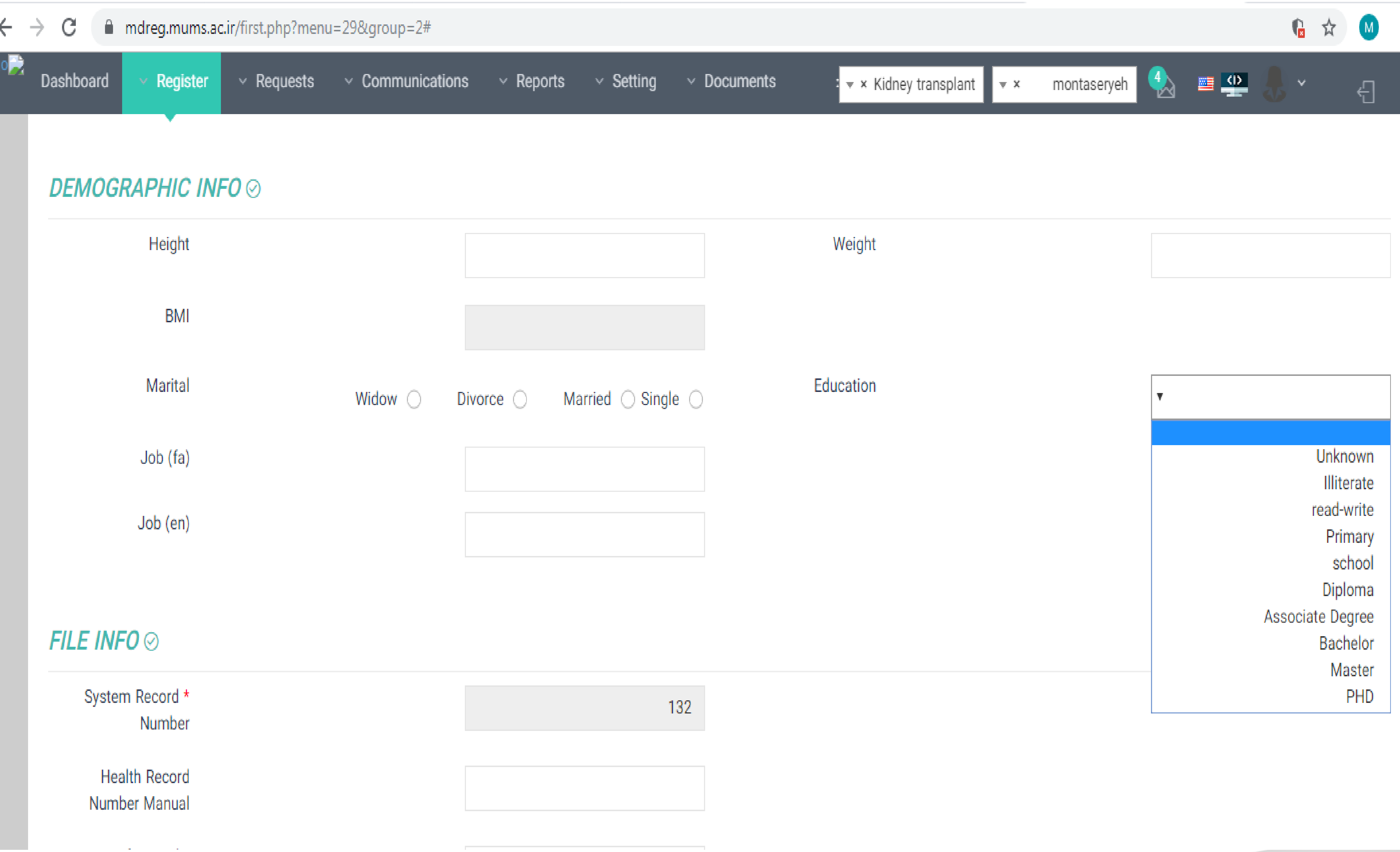
Dashboard

Dashboard

DEATH	HOSPITALIZATION	KIDNEY TRANSPLANT	COUNT OF REGISTERED PATIENT
0	25	344	350

RECIPIENT FOLLOWUP
148


Documents
Setting
Reports
Communications
Requests
Register
Dashboard
4
montaseryeh
dney transplant
900
850
800
750
700
650
600
550
500
450
400
350
300
250
200
150
100
50
0
133
23
15
147
197
349
Doctor maryam hami
Initial registration
Kidney transplant- Temporary
Kidney transplant- Final
Hospitalization- Temporary
Hospitalization- Final
Death- Temporary
Death- Final
Recipient Followup- Temporary



DEMOGRAPHIC INFO

Height

Weight

BMI

Marital Widow ○ Divorce ○ Married ○ Single ○

Education

- Unknown
- Illiterate
- read-write
- Primary school
- Diploma
- Associate Degree
- Bachelor
- Master
- PHD

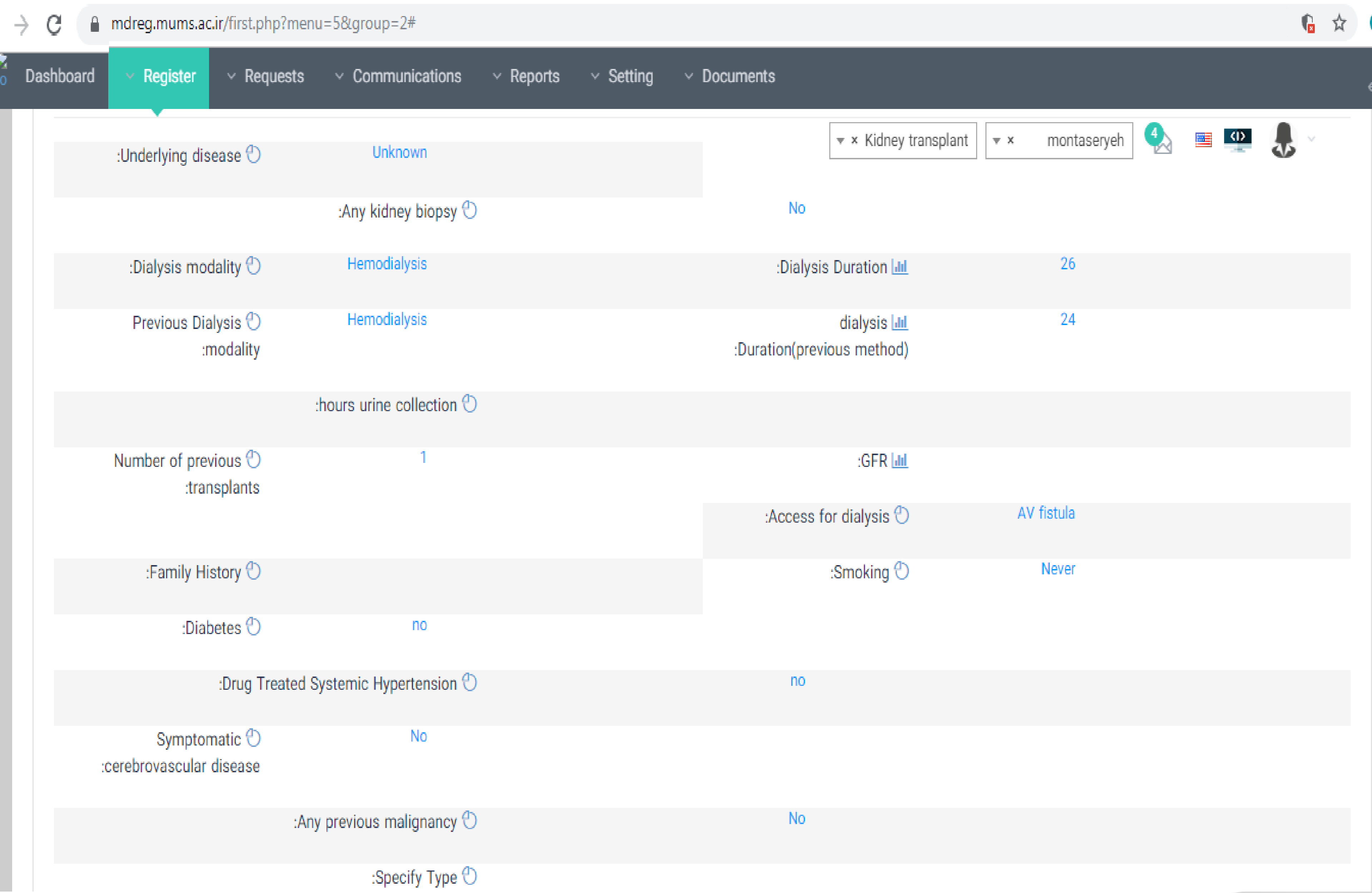
Job (fa)

Job (en)

FILE INFO

System Record * Number: 132

Health Record Number Manual



:Underlying disease	Unknown
:Any kidney biopsy	No
:Dialysis modality	Hemodialysis
:Dialysis Duration	26
Previous Dialysis :modality	Hemodialysis
dialysis :Duration(previous method)	24
:hours urine collection	
Number of previous :transplants	1
:GFR	
:Access for dialysis	AV fistula
:Family History	
:Smoking	Never
:Diabetes	no
:Drug Treated Systemic Hypertension	no
Symptomatic :cerebrovascular disease	No
:Any previous malignancy	No
:Specify Type	

The point of view in RTX registry in some other countries

- Before preparing the registry program in our center, data collection for registration and tracking was done by using paper with manual computer input, similar to the Japanese Renal Transplant Registry before 2009.

K. Yuzawa et al. Transplantation Proceedings, 42, 4010–4013 (2010)

- The Collaborative Brazilian Pediatric Renal Transplant Registry catch the capability to report their patients' survival and graft outcome in 2004 in whole of Brazil.

C Garcia et al. Transplantation Proceedings, 47, 950e953 (2015)

Our place right now:

- There are a few RTX registry systems in some transplantation centers in Iran.
- We prepare a registry program for our local transplantation center in northeast of Iran in the great Khorasan.
- Until now we don't have a single integrated registry program in kidney transplantation centers in Iran.

Final Aim:

- Preparing of a unique registry program in Iran helps to all physicians who works on kidney transplantation have a better estimation of condition of this matter in Iran and can help ministry of health to plan a more suitable and pervasive program for the future.