

Do armazenamento ao uso dos dados em saúde: REDCap e R

Karlyse Claudino Belli

Conflito de interesse

♥ REDCap & R ♥

Registros Clínicos

REDCap: API

R: Shiny

REGISTROS CLÍNICOS

O que é um registro clínico?



The National Committee on Vital and Health Statistics defines a registry as “an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes [them] to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects” .

Coleta + Armazenamento + Consulta + Análise + Disseminação

O que é um registro clínico?



Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

O que é um registro clínico?



Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

Fins de:

Pesquisa
Clínicos
Qualidade
Políticos

O que é um registro clínico?



Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

**Mundo
real**

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PERFORMANCE MEASURES

ACC/AHA/STS Statement on the Future of Registries and the Performance Measurement Enterprise

A Report of the American College of Cardiology/American Heart Association Task Force on
Performance Measures and The Society of Thoracic Surgeons



Role of Registries in the Cycle of Quality

```
graph TD; Concept --> CE[Clinical Evidence]; CE --> Guidelines; Guidelines --> PI[Performance Indicators]; PI --> MFB[Measurement + Feedback]; MFB --> QI[QI Initiatives]; QI --> Outcomes; Outcomes --> CE; CR[Clinical Registries] --> CE; CR --> Guidelines; CR --> PI; CR --> MFB; CR --> QI; CR --> Outcomes;
```

The diagram illustrates the role of registries in the cycle of quality. The central element is **Clinical Registries** (red box). It connects to **Clinical Evidence** (top), **Guidelines** (top right), **Performance Indicators** (bottom right), **Measurement + Feedback** (bottom), **QI Initiatives** (bottom left, orange box), and **Outcomes** (left). Arrows show a clockwise cycle: **Concept** to **Clinical Evidence**, **Clinical Evidence** to **Guidelines**, **Guidelines** to **Performance Indicators**, **Performance Indicators** to **Measurement + Feedback**, **Measurement + Feedback** to **QI Initiatives**, **QI Initiatives** to **Outcomes**, **Outcomes** to **Clinical Evidence**, and **Clinical Registries** to all other components.

Clinical Evidence

Clinical Registries

QI Initiatives

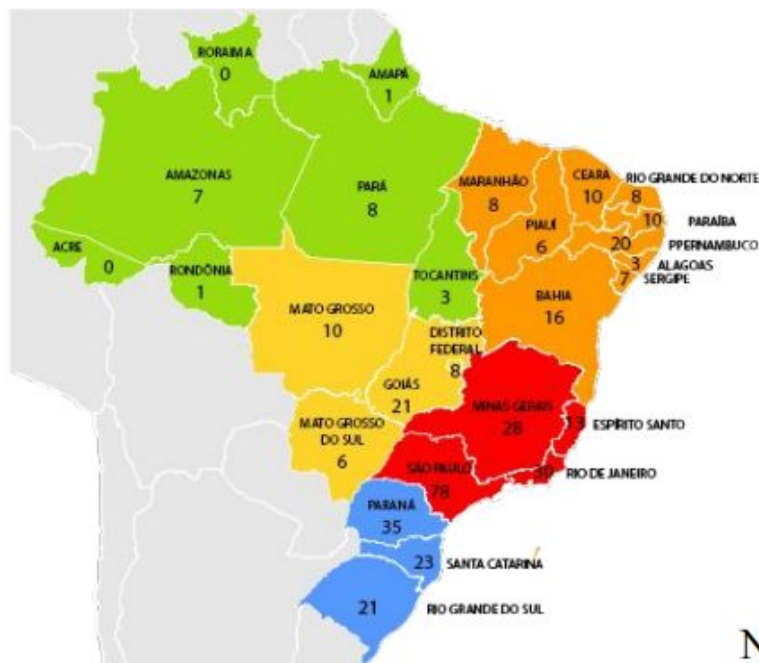
Performance Indicators

Measurement + Feedback

Bhatt DL et al. ACC/AHA/STS. JACC 2015;66:2230-2245.
Califf RM et al. ACC/AHA. JACC 2002;40:1895-901.

REGISTRO BRASILEIRO DE CIRURGIAS CARDIOVASCULARES EM ADULTOS BYPASS

BRAZILIAN SOCIETY OF CARDIOVASCULAR SURGERY



Distribution of hospitals
performing cardiovascular
surgery per Brazilian states

Territory	8,515,767.049 Km ²
Population	207,110,490 inhabitants
Number of states	27
Active Cardiovascular Surgeons in Brazil	1,129
Hospitals Performing Cardiovascular Surgery	381
Cardiovascular operations /year	102,300

The Brazilian Registry of Adult Patient Undergoing Cardiovascular Surgery, the BYPASS Project: Results of the First 1,722 Patients

"A journey of a thousand miles begins with one step."

Lao Tzu

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Table 1. Participating sites and Principal Investigators (PI).

Instituto de Cardiologia do Rio Grande do Sul – Fundação Universitária de Cardiologia – Porto Alegre, RS, Brazil – Renato Abdala Karam Kalil
Hospital Evangélico – Cachoeiro de Itapemirim, ES, Brazil – Lisandro Gonçalves Azeredo
Instituto de Cardiologia do Distrito Federal – Brasília, DF, Brazil – Fernando Antibas Atik
Instituto de Cirurgia Cardiovascular (ICCV)/Hospital Nossa Senhora da Salette – Cascavel, PR, Brazil – Marcelo Pandolfo
Hospital São Vicente de Paulo – Jundiaí, SP, Brazil – Alexandre Cabral Zilli
Instituto de Medicina Integral Professor Fernando Figueira (IMIP) – Recife, PE, Brazil – Fernando Augusto Marinho dos Santos Figueira
Instituto do Coração de Natal – Natal, RN, Brazil – Anilton Bezerra Rodrigues Junior
Hospital Universitário de Santa Maria – Santa Maria, RS, Brazil – Sergio Nunes Pereira
Irmandade da Santa Casa de São Paulo/Faculdade de Ciências Médicas da Santa Casa de São Paulo – São Paulo, SP, Brazil – Valquíria Pelisser Campagnucci
Instituto de Moléstias Cardiovasculares (IMC) – São José do Rio Preto, SP, Brazil – Roberto Vito Ardito
Hospital do Coração de Sergipe – Aracaju, SE, Brazil – José Teles de Mendonça

17
centros
participantes

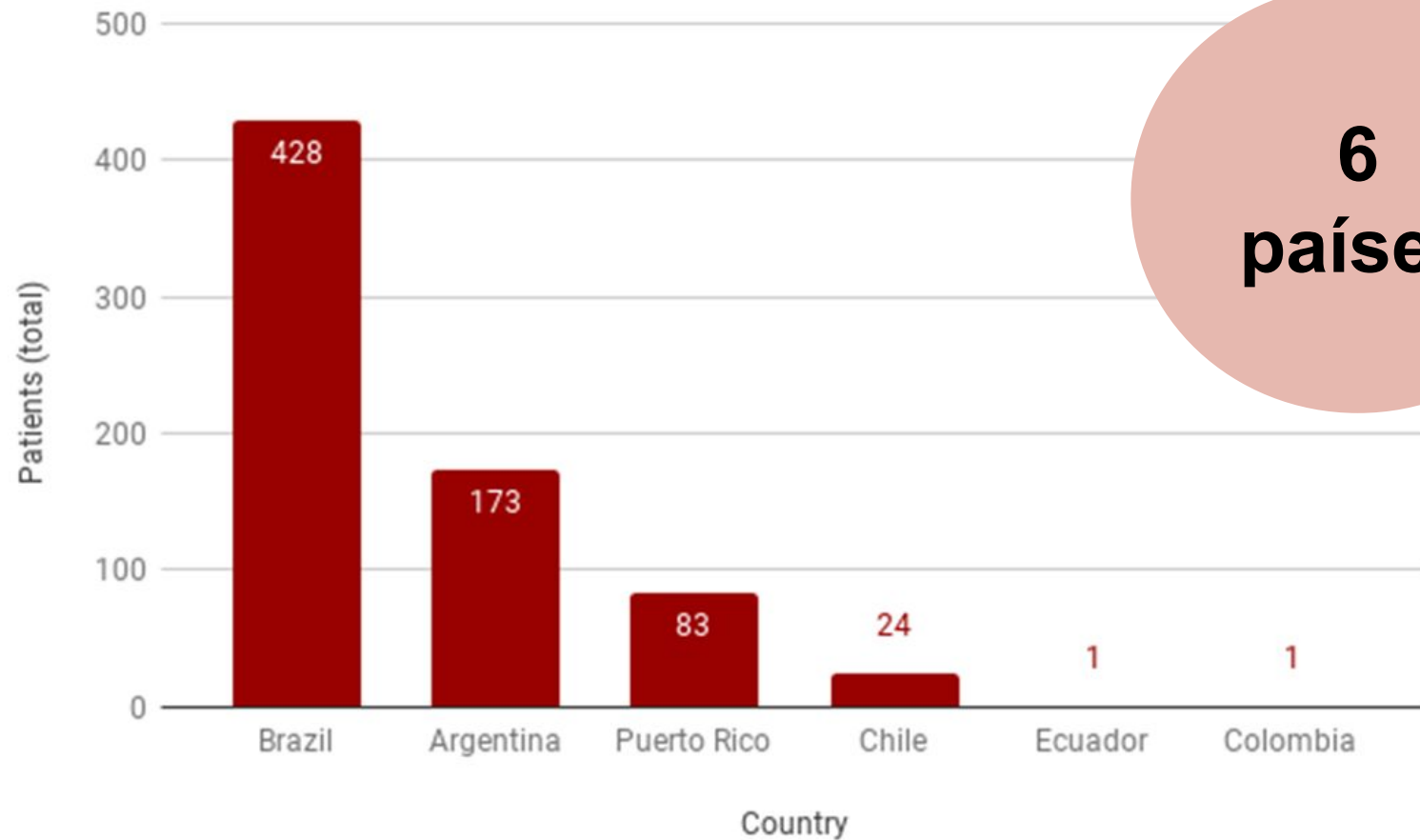
Instituto de Cardiologia do Rio Grande do Sul – Fundação
Universitária de Cardiologia – Porto Alegre, RS, Brazil – Renato
Abdala Karam Kalil

Hospital Wilson Rosado – Mossoró, RN, Brazil – Renato Max Faria
Hospital Bosque da Saúde – São Paulo, SP, Brazil – Rodrigo
Pereira Paez

LATAM CTO Registry



LATAM CTO Registry

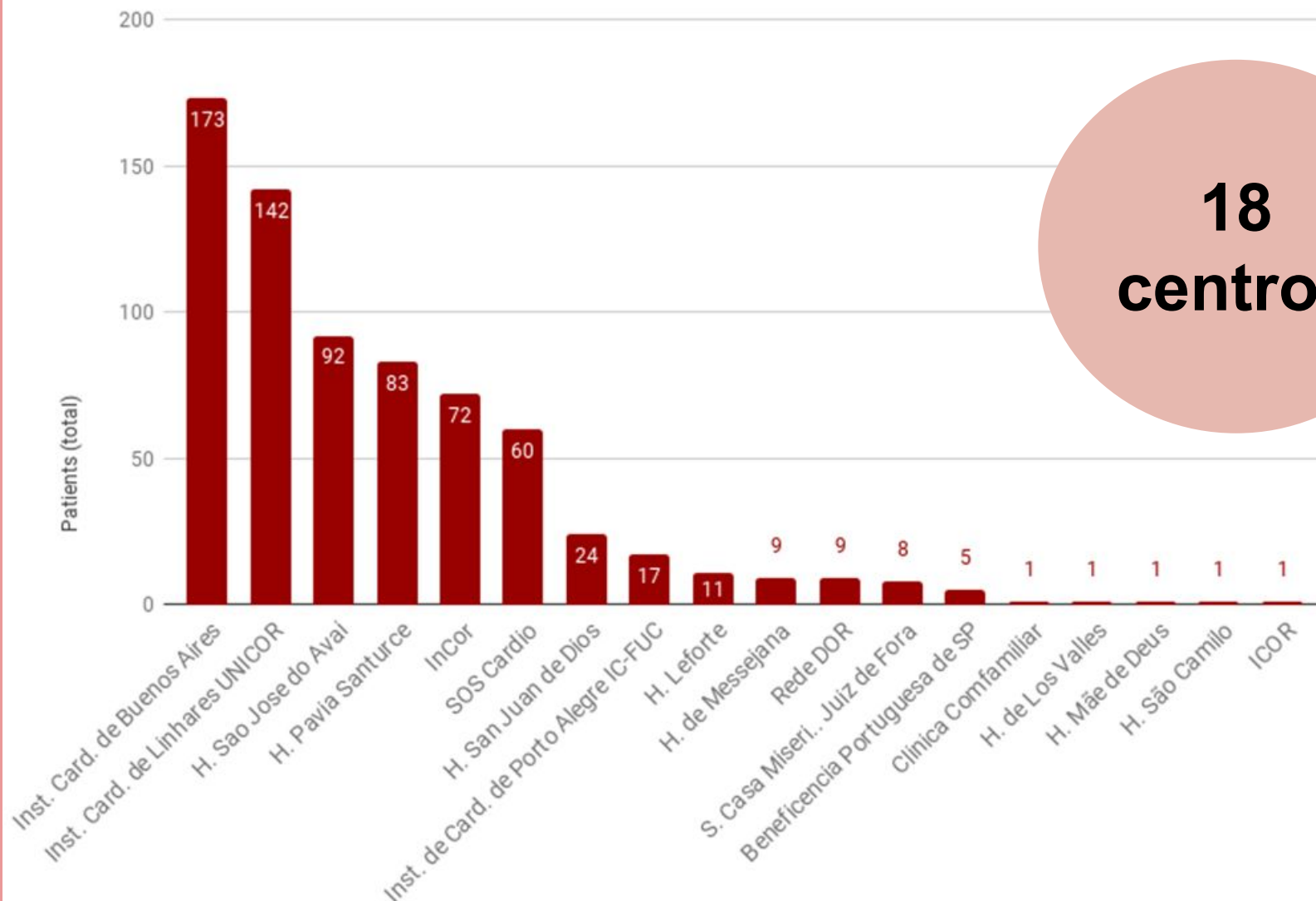


**6
países**

LATAM CTO Registry



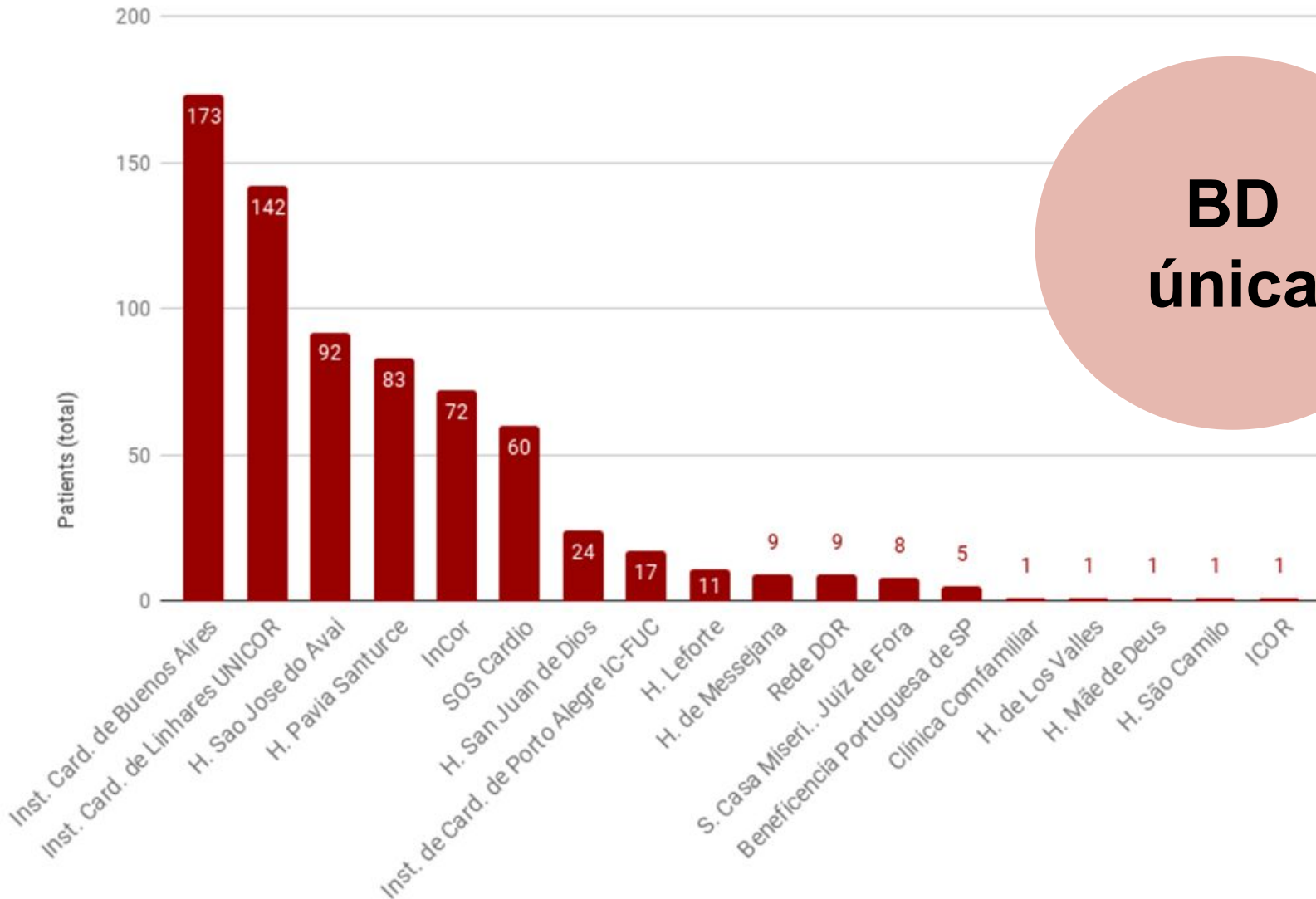
**18
centros**



LATAM CTO Registry




**BD
única**



REDCap

REDCap

← → ↻ Seguro | https://www.project-redcap.org



Institutions

3003

Countries

125

Projects

572k

Users

769k

Articles

5581

ABOUT

PARTNERS

RESOURCES

SOFTWARE

Basic Demography Form

On the web and in a mobile app

Please complete the survey below.

Thank you!

Contact Information

1) First Name

2) Last Name

3) Street, City, State, ZIP

4) Phone number

Basic Demography Form

Please complete the survey below.

Thank you!

Contact Information

1) First Name

2) Last Name

3) Street, City, State, ZIP

4) Phone number

5) E-mail

REDCap

For Office Data Collection

My Profile

My Data Collection

My Data Collection

My Data Collection

My Data Collection

My Data Collection

REDCap is a secure web application for building and managing online surveys and databases. While REDCap can be used to collect virtually any type of data (including 21 CFR Part 11, FISMA, and HIPAA-compliant environments), it is specifically geared to support online or offline data capture for research studies and operations. The REDCap Consortium, a vast support network of collaborators, is composed of thousands of active institutional partners in over one hundred countries who utilize and support REDCap in various ways.

LEARN MORE



Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

Logged in as **coordenacao** | Log out

My Projects or Control Center

Project Home

Project Setup

Project status: **Production**

Data Collection

- Scheduling
- Record Status Dashboard
- Add / Edit Records

Record ID 1 [Select other record](#)

Applications

- Calendar
- Data Exports, Reports, and Stats
- Data Import Tool
- Data Comparison Tool
- Logging
- Field Comment Log
- File Repository
- User Rights and DAGs
- Record Locking Customization
- E-signature and Locking Mgmt
- Data Quality
- API and API Playground
- REDCap Mobile App

Reports [Edit reports](#)

- 1) Lista com todos os casos do registro
- 2) Todos os pacientes incluídos
- 3) Scores completos
- 4) Outcomes 30 days
- 5) Outcomes 1 year

SBHCI CTO Registry

Record Home Page

Record "1" is a new Record ID. To create the record and begin entering data

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

NEW Record ID 1

Data Collection Instrument	Internação índice	30 dias	1 ano	2 anos
Identificação do paciente				
Dados demográficos				
História médica				
Status pré procedimento				
Angiografia				
Dados do CTO				
ICP do CTO				
Dados do procedimento				
Complicações do procedimento				
Dados laboratoriais				
Desfechos				



REDCap Mobile App

Connected
Julia Simoes
v2.51.10

Hemodinâmica HSF - Avaliação Enfermagem

Recup. Pos procedimento

Show instrument controls

Atendimento 1111

Radial: Curativo compressivo ate as:


Now H:M

Pulseira TR Band ate as:


Now H:M

Femoral - Repouso ate as:


Now H:M

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

Satélite



Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

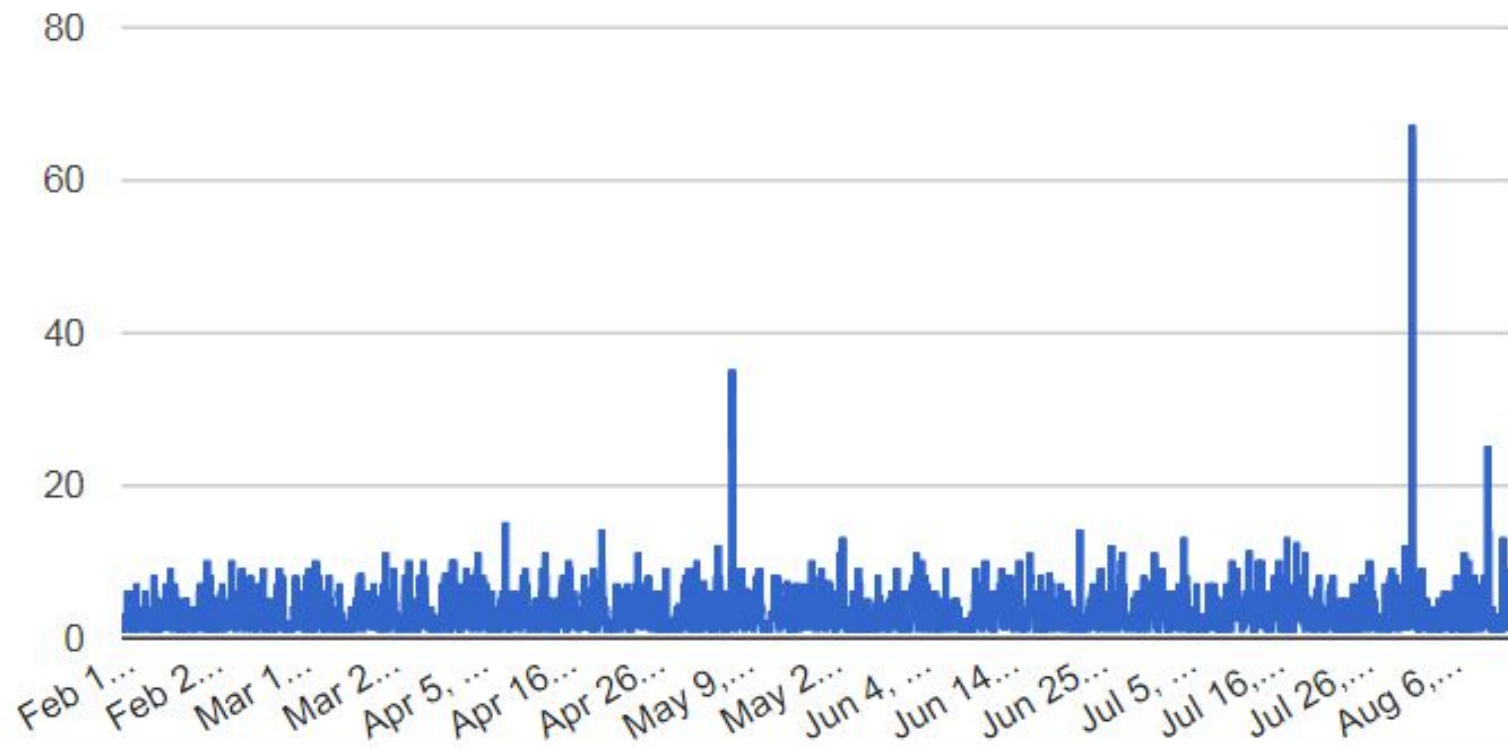
Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

Concurrent Users (Past 6 Months)



Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

Registros (16)						
Registro de Infarto Agudo do Miocárdio (RIAM)	329	202	12 forms			
Registro Clínico de Hipertensão - Re-Hyper	119	665	22 forms			
Registro de Pacientes Participantes em Ensaios Clínicos no IC-FUC (CEPEC)	873	160	10 forms			
Registro de Eletrofisiologia	2.299	161	5 forms			
Registro de Cardiologia Pediátrica Preventiva (PREVINA)	96	445	14 forms			
Registro Prospectivo de Transplante Cardíaco em Adultos	212	466	14 forms			
Registro de Cirurgia Cardiovascular em Adultos	1.581	667	7 forms			
SBHCI CTO Registry	767	200	11 forms			
LogBook Hemodinâmica e Cardiologia Intervencionista	8.875	31	1 form			
Registro DES, Fisiologia e Rota	2.158	299	10 forms			
RE-Endo Registry (2017)	65	626	25 forms			
Registro Cardiologia Fetal	0	7	2 forms			
Registro MAPA	3	34	1 form			
MASCOT	1	202	4 forms			
MASCOT survey	39	30	1 survey			
Center Level Data CTO LATAM 	49	25	1 survey			
+ Ecocardiograma (4)						
+ PPG Ciências da Saúde (3)						
+ PPG Tecnologia e Inovação (1)						
+ PPG Enfermagem (1)						
+ Hemodinâmica (1)						
+ Gerenciais (2)						
+ Treinamentos (23)						

Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

Exporting "All data (all records and fields)"

Select your export settings, which includes the export format (Excel/CSV, SAS, SPSS, R, Stata) and if you wish to perform de-identification on the data set.

Choose export format

☒  CSV / Microsoft Excel (raw data)☐  CSV / Microsoft Excel (labels)☐  SPSS Statistical Software☐  SAS Statistical Software☐  R Statistical Software☐  Stata Statistical Software☐  CDISC ODM (XML)

De-identification options (optional)

The options below allow you to limit the amount of sensitive information that you are exporting out of the project. Check all that apply.

Known Identifiers:

- ☐ Remove all tagged Identifier fields (tagged in Data Dictionary)
- ☐ Hash the Record ID field (converts record name to an unrecognizable value)

Free-form text:

- ☐ Remove unvalidated Text fields (i.e. Text fields other than dates, numbers, etc.)
- ☐ Remove Notes/Essay box fields

Date and datetime fields:

- ☐ Remove all date and datetime fields
- OR —
- ☐ Shift all dates by value between 0 and 364 days (shifted amount determined by algorithm for each record) [What is date shifting?](#)

[Deselect all options](#)

Additional export options

- ☒ Export Data Access Group name for each record (if record is in a group?)

Export Data

Cancel

Delete	487
Delete	355
Delete	486
Delete	494
Delete	495
Delete	496
Delete	502

Scheduling
Record Status Dashboard
Add / Edit Records

Applications

Calendar
Data Exports, Reports, and Stats
Data Import Tool
Data Comparison Tool
Logging
Field Comment Log
File Repository
User Rights and DAGs
Record Locking Customization
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REDCap Mobile App

Reports

✎ Edit report

- 1) Lista com todos os casos do registro
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- 3) Scores completos
- 4) Outcomes 30 days
- 5) Outcomes 1 year
- 6) Outcomes 2 years
- 7) Data do procedimento

Help & Information

view it as a report, then Report A is the best and quickest way. However, if you want to view or export data from only specific instruments (or events) on the fly, then Report B is the best choice. You may also create your own custom reports below (if you have such privileges) in which you can filter the report to specific fields, records, or events using a vast array of filtering tools to make sure you get the exact data you want. Once you have created a report, you may view it as a webpage, export it out of REDCap in a specified format (Excel, SAS, Stata, SPSS, R), or view the plots and descriptive statistics for that report.

My Reports & Exports

Management Options

✔ Data export was successful!

The data export was successful, and your data is now ready to be downloaded. Click the download icon(s) below on the right to download your data file. If exporting to a specific statistical analysis package, you will additionally need to download the syntax file that is provided for that stats package. For more details, follow the instructions in the box below.

Citation Notice

Please **cite the REDCap project when publishing manuscripts** (citation information and template methods language are [available here](#)).



R Statistical Software

Instructions: Use command `read.csv('filename')` to read in data file.

Click icon(s) to download:



📧 Send file?

Close

API = 'Application Programming Interface'



Interface que permite que aplicativos externos se conectem remotamente ao REDCap.

execução de importações de dados automatizadas

Os programas conversam com a API do REDCap sobre HTTP, o mesmo protocolo que seu navegador usa para visitar e interagir com páginas da web.

API = 'Application Programming Interface'



SBHCI CTO Registry | REDCap

← → ↻ Não seguro | redcap.cardiologia.org.br/redcap/redcap_v7.2.0/API/project_api.php?pid=108

Logged in as **coordenacao** | Log out

My Projects or Control Center

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6) Outcomes 2 years

7) Data do procedimento

SBHCI CTO Registry

API

The REDCap API is an interface that allows external applications to connect to REDCap remotely, and is used for programmatically retrieving or modifying data or settings within REDCap, such as performing automated data imports/exports from a specified REDCap project. For details on the capabilities of the REDCap API and how to use it, please see the [REDCap API documentation](#).

My Token Manage All Project Tokens

Your API token for project "SBHCI CTO Registry"

The API token below is **ONLY for you** and will work **ONLY with this project**. This token allows special access to REDCap data and **should NOT be shared with others**. If you think your token has been compromised, then please contact your REDCap administrator immediately **AND** either delete or regenerate your token by using the buttons below.

API Token:

299105D70F

Delete token Finished using the API for this project? If so, please delete your token for security reasons.

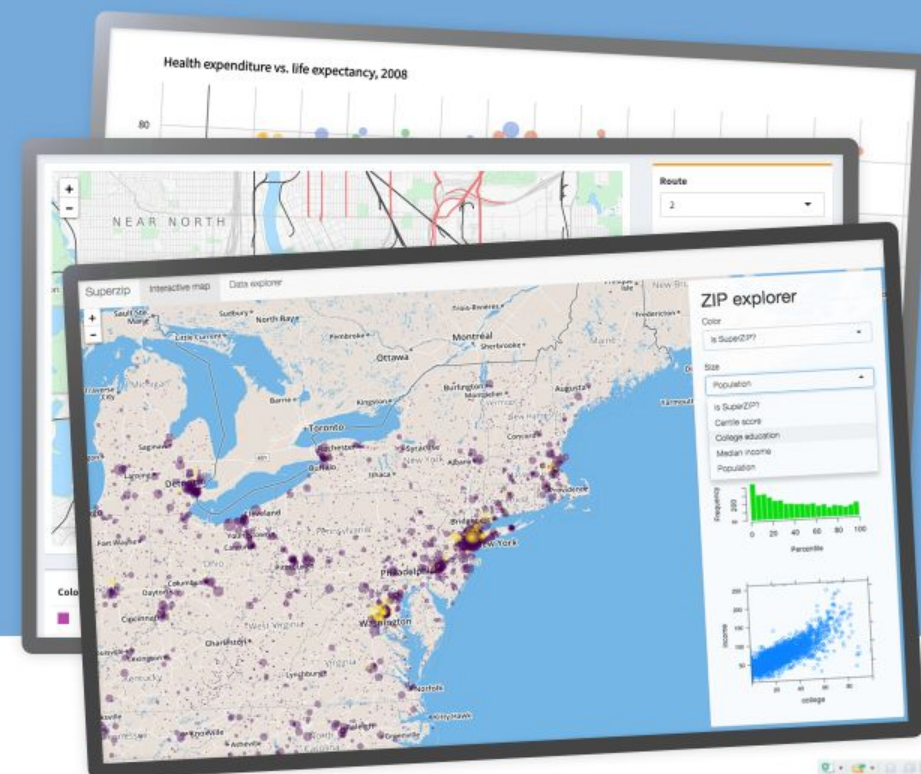
Regenerate token Think someone else knows your token? If so, please regenerate your token for security reasons.

The following user(s) have API tokens for this project: **alesq, coordenacao, pedropiccaro@gmail.com**

Event names for SBHCI CTO Registry

Unique event name	Event Name	Arm
internao_ndice_arm_1	Interação índice	Arm 1
30_dias_arm_1	30 dias	Arm 1
1_ano_arm_1	1 ano	Arm 1

R



Interact. Analyze. Communicate.

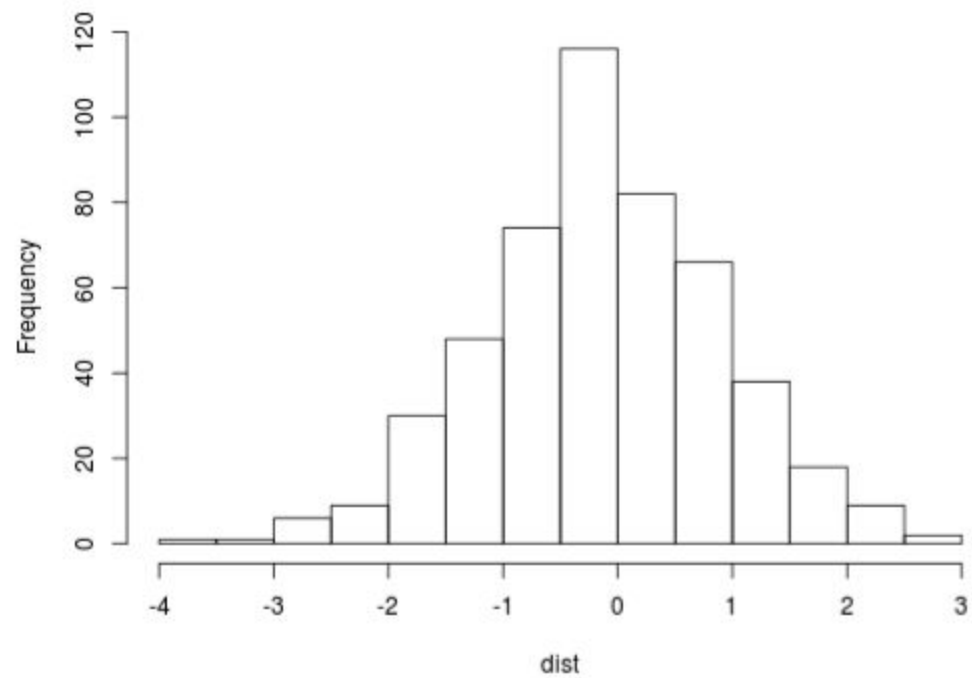
Take a fresh, interactive approach to telling your data story with Shiny. Let users interact with your data and your analysis. And do it all with R.

Hello Shiny!

Number of observations:



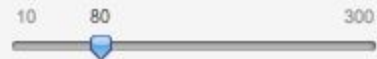
Histogram of dist



Movie explorer

Filter

Minimum number of reviews
on Rotten Tomatoes



Year released



Minimum number of Oscar
wins (all categories)



Dollars at Box Office
(millions)

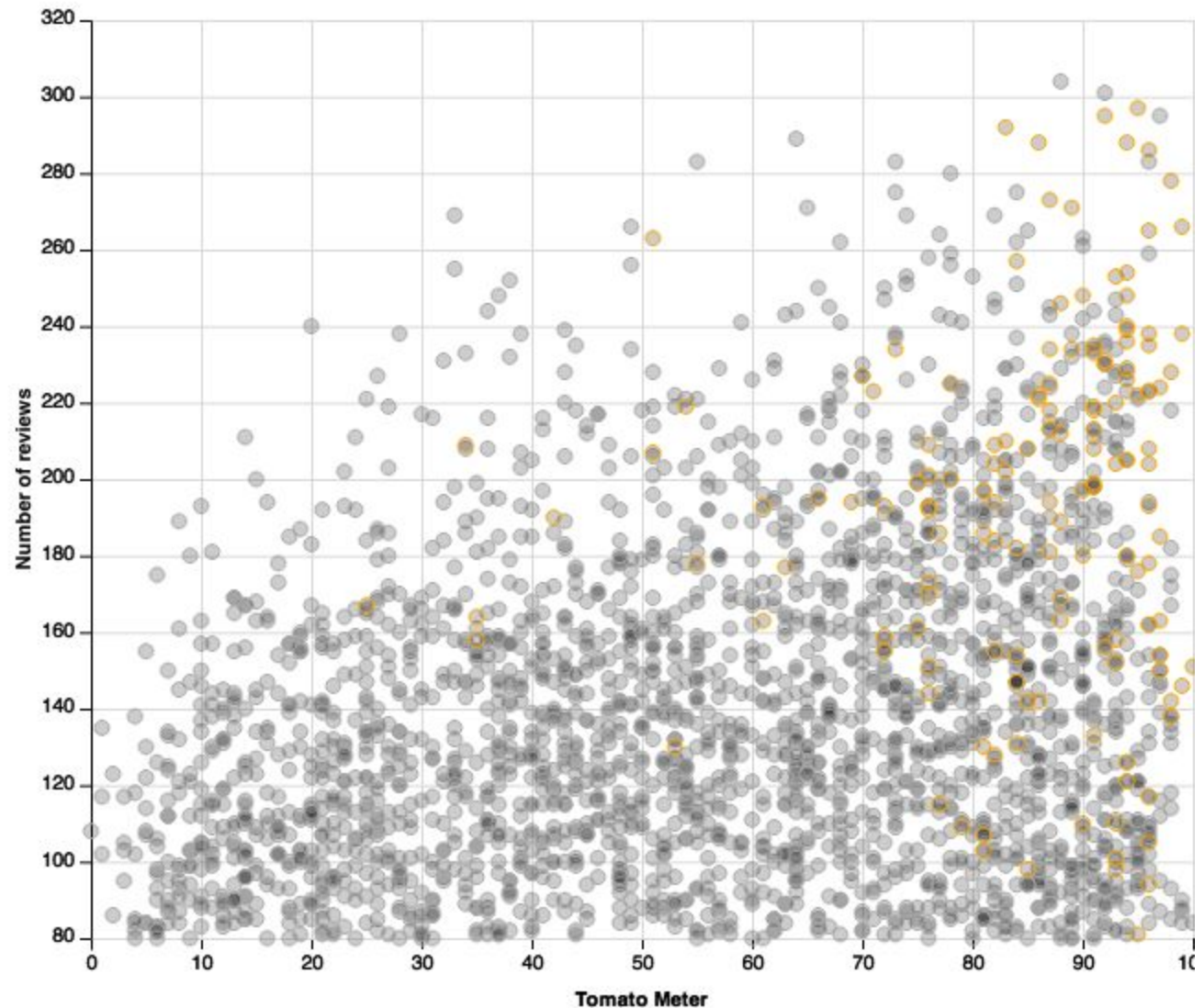


Genre (a movie can have
multiple genres)

All ▼

X-axis variable

Tomato Meter ▼



Programação

A screenshot of the RStudio IDE. The top menu bar includes File, Edit, Code, View, Plots, Session, Build, Debug, Profile, Tools, and Help. Below the menu is a toolbar with icons for saving, running, and other functions. The main editor window shows a script named 'app.R' with R code for a Shiny application. The code includes library calls for 'shiny' and 'shinythemes', setting the working directory, and defining a UI with a navbar, sidebar, and main panel. The server function is also partially visible.

```
1 library(shiny)
2 library(shinythemes)
3
4 setwd("C:/Users/Usuario/Desktop/SBHCI")
5 source("sintaxe.R")
6
7 # Define UI for application that draws a histogram
8 ui <- navbarPage(title = img(src = "sbhci.png", height = "45px"), theme = "spacelab", windowTitle = "LATAM CTO Registry",
9                 tabPanel("Presentation",
10                          sidebarLayout(
11                            sidebarPanel(p("LATAM CTO Registry"),
12                                         br(),
13                                         p("we started our LATAM CTO Registry JANEIRO DE 2018 and we have already included 638 patients"),
14                                         br(),
15                                         p("There are many ways the registry can contribute to this field with original investigations"),
16                                         br(),
17                                         p("we have already sent abstracts with our initial experience to SBHCI, SOLACI and SBC meetings"),
18                               , width = 4),
19                            mainPanel(
20                              plotlyoutput("mapa", height = 600, width = 800)
21                            )))
22
23 tabPanel("Results"),
24 tabPanel("Participants")
25
26 )
27
28
29 server <- function(input, output) {
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Escolha do tema



United | **Navbar 1** | Plot | Table

File input:

Browse... No file selec

Text input:

general

Slider input:

1 30 100

1 11 21 31 41 51 61 71 81 91 100

Default actionButton:

Search

actionButton with CSS class:

Action button

Tab 1 | **Tab 2** | Tab 3

Table

speed	dist
4.00	2.00
4.00	10.00
7.00	4.00
7.00	22.00

Verbatim text output

general, 30, NULL

Header 1

Header 2

Header 3

Header 4

Header 5

<https://rstudio.github.io/shinythemes/>

Escolha do tema



Readable

Navbar 1

Plot

Table

File input:

Browse...

No file selected

Text input:

general

Slider input:



Default actionButton:

Search

actionButton with CSS class:

Action button

Tab 1

Tab 2

Tab 3

Table

speed	dist
4.00	2.00
4.00	10.00
7.00	4.00
7.00	22.00

Verbatim text output

```
general, 30, NULL
```

Header 1

Header 2

Header 3

Header 4

Header 5

Escolha do tema: spacelab



Spacelab **Navbar 1** Plot Table

File input:

Browse... No file selected

Text input:

general

Slider input:

1 30 100

1 11 21 31 41 51 61 71 81 91 100

Default action button:

Search

action button with CSS class:

Action button

Tab 1 **Tab 2** Tab 3

Table

speed	dist
4.00	2.00
4.00	10.00
7.00	4.00
7.00	22.00

Verbatim text output

general, 30, NULL

Header 1

Header 2

Header 3

Header 4

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<https://rstudio.github.io/shinythemes/>

Componentes da aplicação



LATAM CTO Registry

We started our LATAM CTO Registry in 2018 and we have already included 738 patients in the database. This is a great accomplishment, thanks to the hard work and commitment of everyone involved. As new centers are being included, there is need to keep the pace so we can build a robust and large database to understand the CTO reality in LATAM.

There are many ways the registry can contribute to this field with original investigations, and anyone who has an idea for analysis is more than welcome to suggest it and share with the group, so we can all analyze it together and build up on it.

We have already presented our initial experience to SBHCI and SOLACI meetings, and we are happy to inform that the Brazilian Congress ranked our abstract as one of the top 6 scientific works submitted.

Programação

A screenshot of the RStudio IDE interface. The top menu bar includes File, Edit, Code, View, Plots, Session, Build, Debug, Profile, Tools, and Help. Below the menu is a toolbar with icons for file operations and a 'Go to file/function' search bar. The main editor window shows an R script named 'app.R' with the following code:

```
25
26 )
27
28
29 server <- function(input, output) {
30
31   output$mapa <- renderPlotly({
32
33     p <- ggplot(shape)+
34       theme_minimal()+
35       geom_polygon( aes(x = long, y = lat, group = group, fill= shape$freq), color = "lightgray", alpha = 3/5) +
36       coord_map()+
37       scale_fill_distiller(name = "Número de pacientes",
38                           palette = "Reds", direction = "1")+
39       labs(x="", y="")+
40       #geom_text(aes(label = freq, x = Long, y = Lat)) +
41       theme(axis.text=element_blank()+
42             theme(legend.position = "bottom")
43
44     ggplotly(p + geom_point(data = localizacao, mapping = aes(x = lon, y = lat)))
45   })
46 }
47
48
```

The status bar at the bottom indicates '(Top Level)' and 'R Script'.

Componentes da aplicação

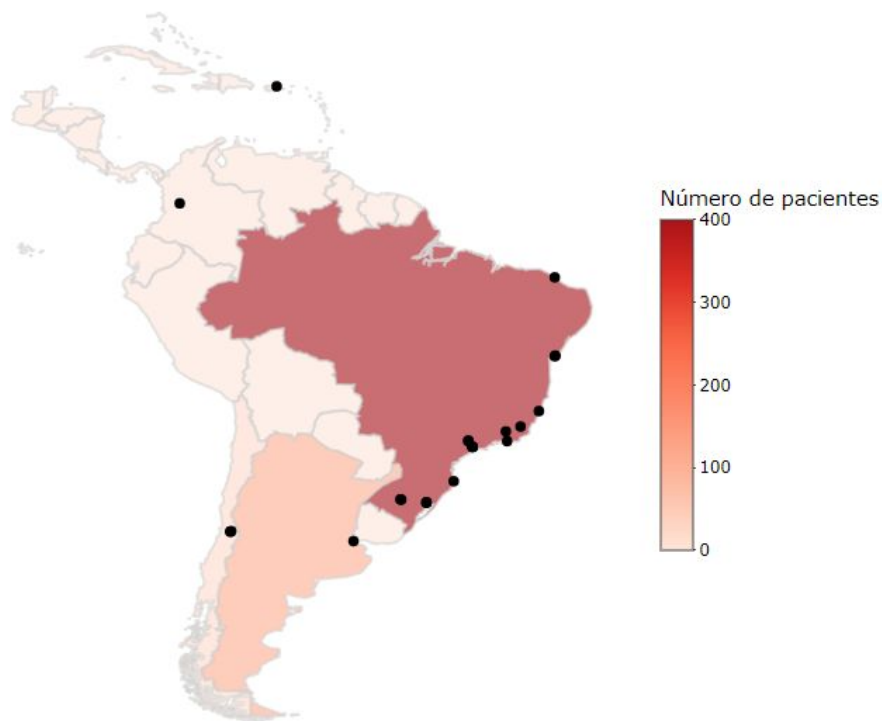


LATAM CTO Registry

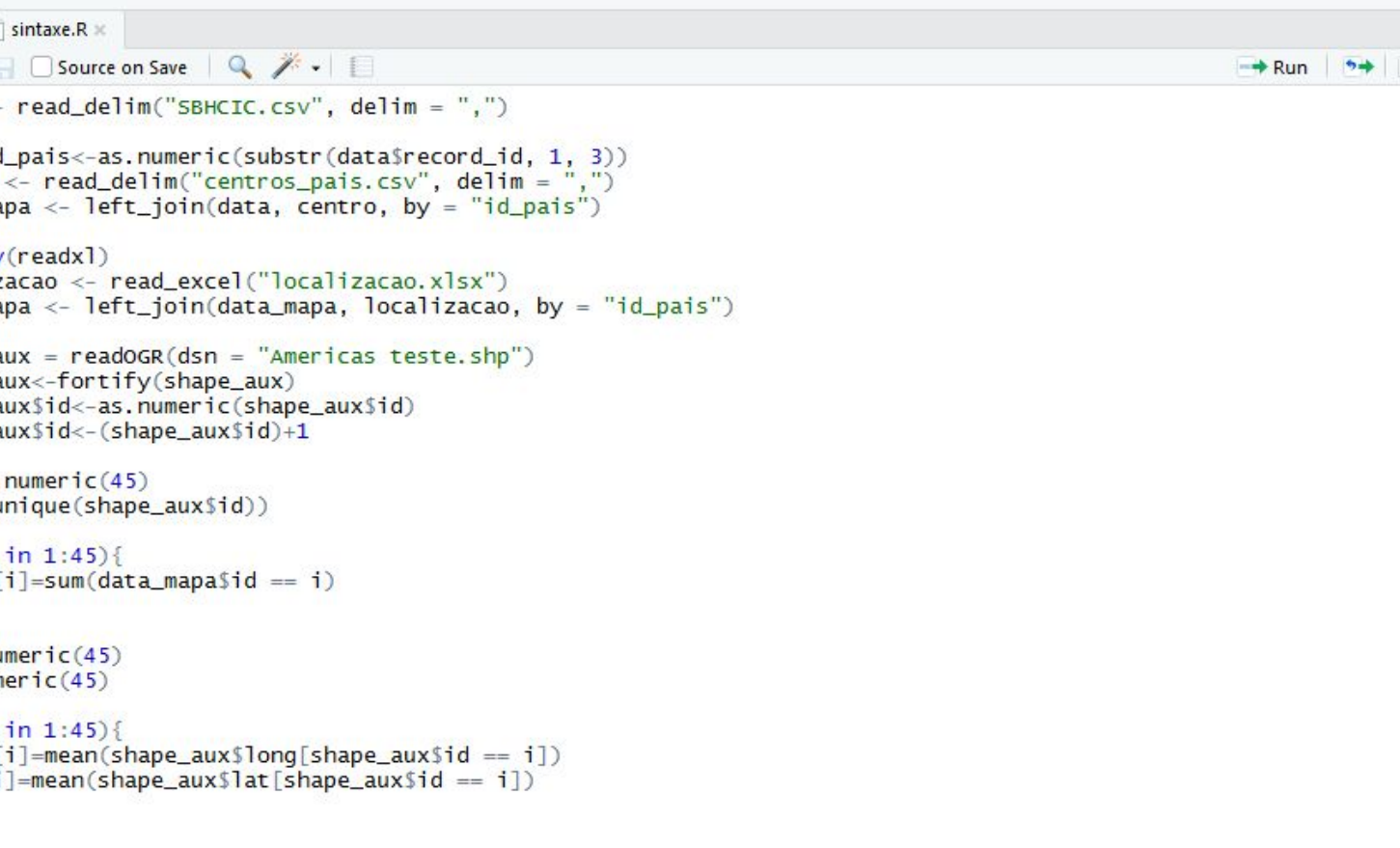
We started our LATAM CTO Registry in 2018 and we have already included 738 patients in the database. This is a great accomplishment, thanks to the hard work and commitment of everyone involved. As new centers are being included, there is need to keep the pace so we can build a robust and large database to understand the CTO reality in LATAM.

There are many ways the registry can contribute to this field with original investigations, and anyone who has an idea for analysis is more than welcome to suggest it and share with the group, so we can all analyze it together and build up on it.

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Programação



The screenshot shows the RStudio IDE with a script editor containing R code. The code reads two CSV files, joins them, reads an Excel file, joins it, reads a shapefile, and calculates the frequency and mean longitude/latitude for each unique ID. The code is as follows:

```

12 data <- read_delim("SBHCIC.csv", delim = ",")
13
14 data$id_pais<-as.numeric(substr(data$record_id, 1, 3))
15 centro <- read_delim("centros_pais.csv", delim = ",")
16 data_mapa <- left_join(data, centro, by = "id_pais")
17
18 library(readxl)
19 localizacao <- read_excel("localizacao.xlsx")
20 data_mapa <- left_join(data_mapa, localizacao, by = "id_pais")
21
22 shape_aux = readOGR(dsn = "Americas teste.shp")
23 shape_aux<-fortify(shape_aux)
24 shape_aux$id<-as.numeric(shape_aux$id)
25 shape_aux$id<-(shape_aux$id)+1
26
27 freq = numeric(45)
28 id = (unique(shape_aux$id))
29
30 for (i in 1:45){
31   freq[i]=sum(data_mapa$id == i)
32 }
33
34 Long=numeric(45)
35 Lat=numeric(45)
36
37 for (i in 1:45){
38   Long[i]=mean(shape_aux$long[shape_aux$id == i])
39   Lat[i]=mean(shape_aux$lat[shape_aux$id == i])
40 }
41
42
43 data_mapa = data.frame(id, freq, Long, Lat)
44 data_mapa$Long[data_mapa$freq == 0]=NA
45 data_mapa$Lat[data_mapa$freq == 0]=NA

```

The status bar at the bottom indicates the cursor is at line 1:1, column 1, and the script is running.

Package 'redcapAPI'

August 1, 2018

Type Package

Title Interface to 'REDCap'

Version 2.2

Maintainer Benjamin Nutter <benjamin.nutter@gmail.com>

Description Access data stored in 'REDCap' databases using the Application Programming Interface (API). 'REDCap' (Research Electronic Data CAPture; <<https://projectredcap.org>>) is a web application for building and managing online surveys and databases developed at Vanderbilt University. The API allows users to access data and project meta data (such as the data dictionary) from the web programmatically. The 'redcapAPI' package facilitates the process of accessing data with options to prepare an analysis-ready data set consistent with the definitions in a database's data dictionary.

License GPL-2

Depends R (>= 3.0.0)

Imports checkmate, chron, DBI, httr, labelVector, lubridate, readr, stringr, tidyr

LazyLoad yes

Registros Clínicos

REDCap: API

R: Shiny

Do armazenamento ao uso dos dados em saúde: REDCap e R

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