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

JACC 2015;66:2230-2245
https://www.ncvhs.hhs.gov/9701138b.htm

O que é um registro clínico?

Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

JACC 2015;66:2230-2245
Circulation. 2011;123:2167-79

O que é um registro clínico?

Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

Fins de:

Pesquisa
Clínicos
Qualidade
Políticos

JACC 2015;66:2230-2245
Circulation. 2011;123:2167-79

O que é um registro clínico?

Base de dados - observacional

Foco em:

- Condições clínicas
- Procedimentos
- Terapias
- Populações

Mundo real

JACC 2015;66:2230-2245
Circulation. 2011;123:2167-79

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY
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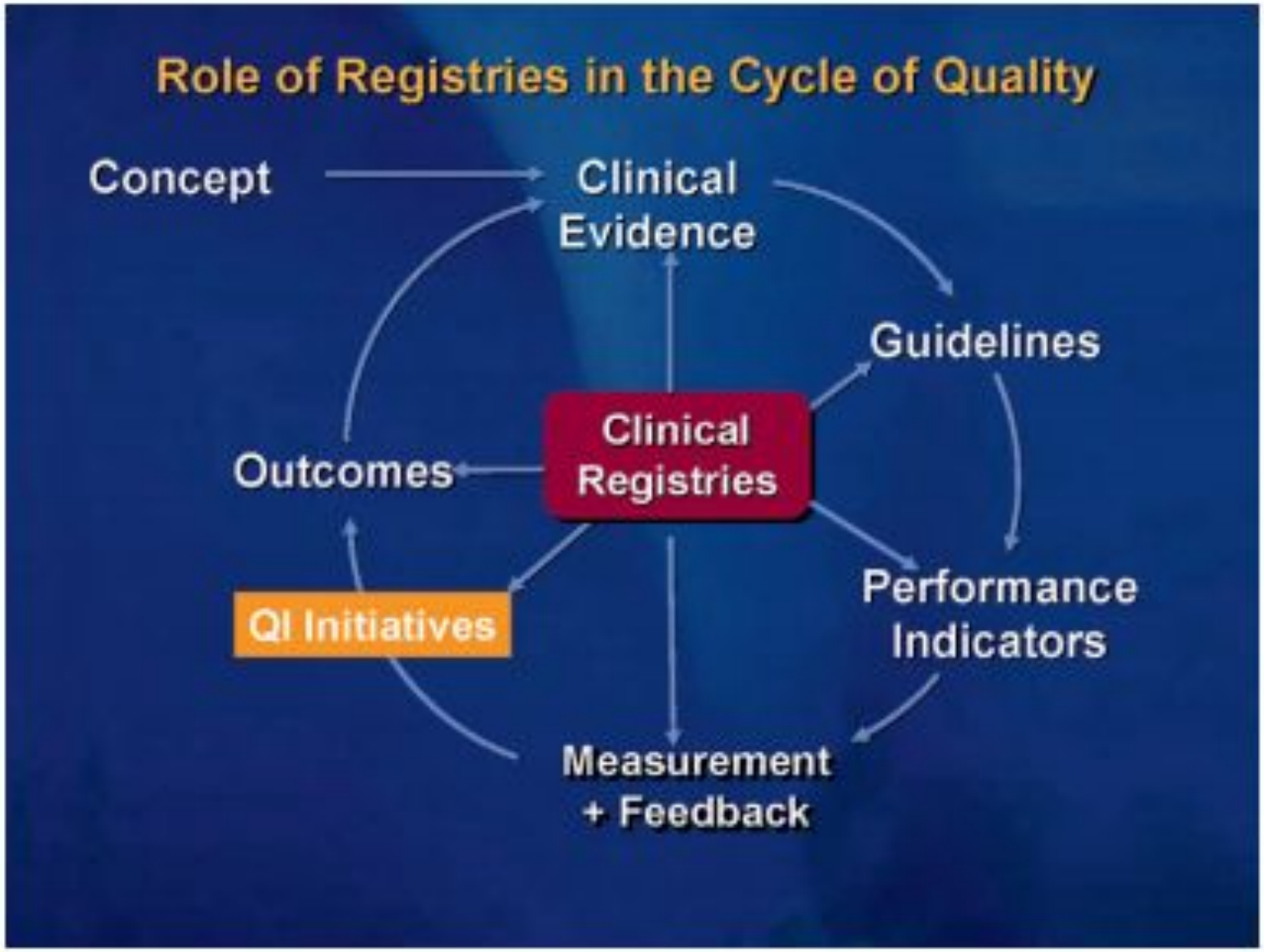
VOL. 66, NO. 20, 2015
ISSN 0735-1097/$36.00
http://dx.doi.org/10.1016/j.jacc.2015.07.010

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

JACC 2015;66:2230-2245.



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 Km²
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

Sociedade Brasileira De Cirurgia Cardiovascular

HCor Instituto de Pesquisa

bypass REGISTRY

Imagens e informações cedidas pela Equipe Coordenadora do Estudo BYPASS

ORIGINAL ARTICLE

Braz J Cardiovasc Surg 2017;32(2):71-6

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

Walter J. Gomes[1], MD, MSc, PhD; Rita Simone Moreira[1], RN, MSc, PhD; Alexandre Cabral Zilli[2], MD; Luiz Carlos Bettiati Jr[2], MD; Fernando Augusto Marinho dos Santos Figueira[3], MD; Stephanie Steremberg Pires D'Azevedo[3], RN; Marcelo José Ferreira Soares[4], MD; Marcio Pimentel Fernandes[4], MD; Roberto Vito Ardito[5], MD; Renata Andrea Barberio Bogdan[5], MD; Valquíria Pelisser Campagnucci[6], MD, MSc, PhD; Diana Nakasako[6], MD; Renato Abdala Karam Kalil[7], MD, MSc, PhD; Clarissa Garcia Rodrigues[7], RN, MSc, PhD; Anilton Bezerra Rodrigues Junior[8], MD; Marcelo Matos Cascudo[8], MD; Fernando Antibas Atik[9], MD, PhD; Elson Borges Lima[9], MD; Vinicius José da Silva Nina[10], MD, PhD; Renato Albuquerque Heluy[10]; Lisandro Gonçalves Azeredo[11], MD; Odilon Silva Henrique Junior[11], MD; José Teles de Mendonça[12], MD, PhD; Katharina Kelly de Oliveira Gama Silva[12]; Marcelo Pandolfo[13], MD; José Dantas de Lima Júnior[13], MD, MSc; Renato Max Faria[14], MD; Jonas Gonçalves dos Santos[14], MD; Rodrigo Pereira Paez[15], MD; Guilherme Henrique Biachi Coelho[15], MD; Sergio Nunes Pereira[16], MD; Roberta Senger[16], RN; Enio Buffolo[17], MD, PhD; Guido Marco Caputi[17], MD, PhD; José Amalth do Espírito Santo[18], MD; Juliana Aparecida Borges de Oliveira[18], RN; Otavio Berwanger[18], MD, PhD; Alexandre Biasi Cavalcanti[18], MD, PhD; Fabio B. Jatene[19], MD, PhD

EDITOR HIGHLIGHT

DOI: 10.21470/1678-9741-2017-0053

17
centros
participantes

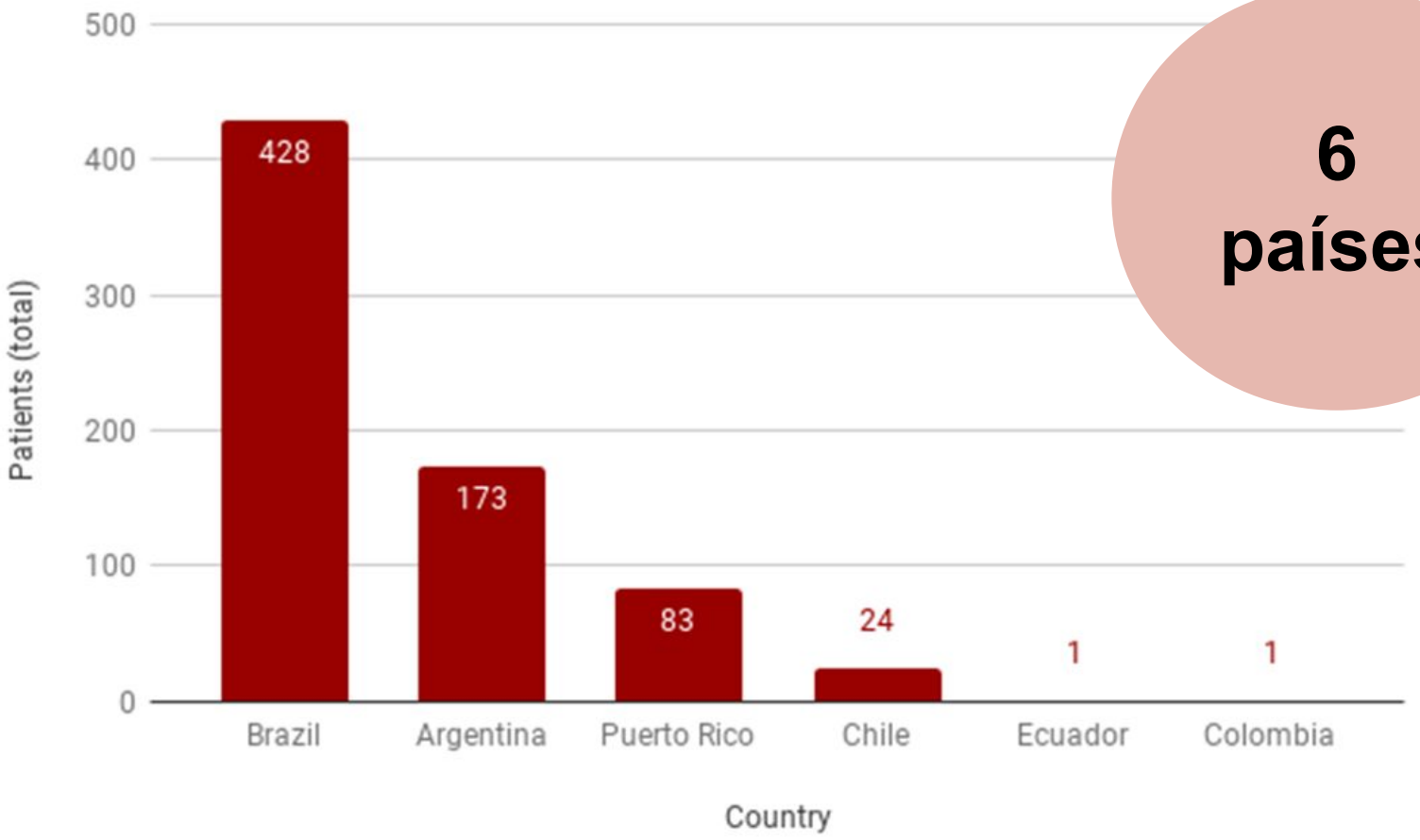
Table 1. Participating sites and Principal Investigators (PI).

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

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

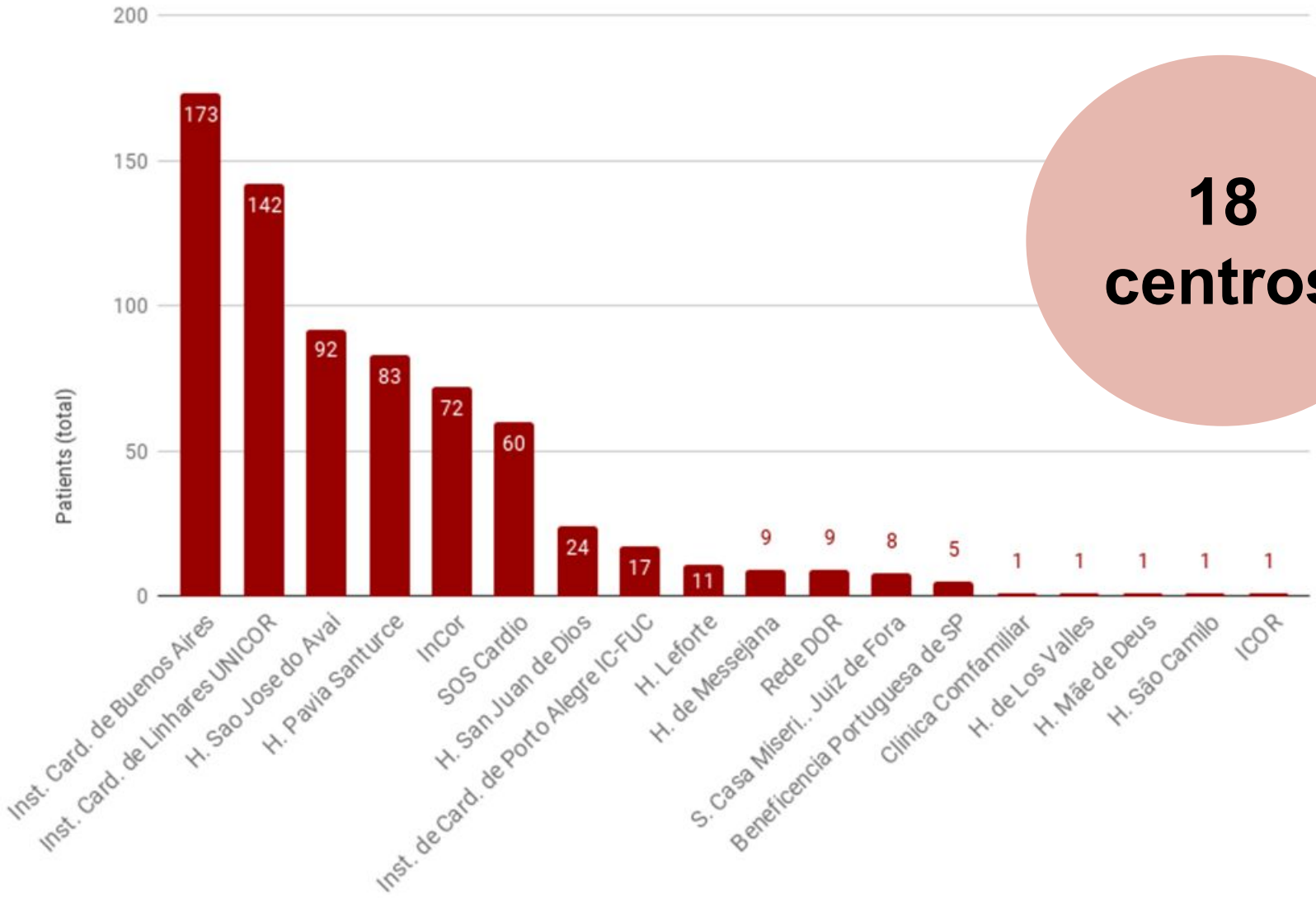
LATAM CTO Registry

LATAM CTO Registry



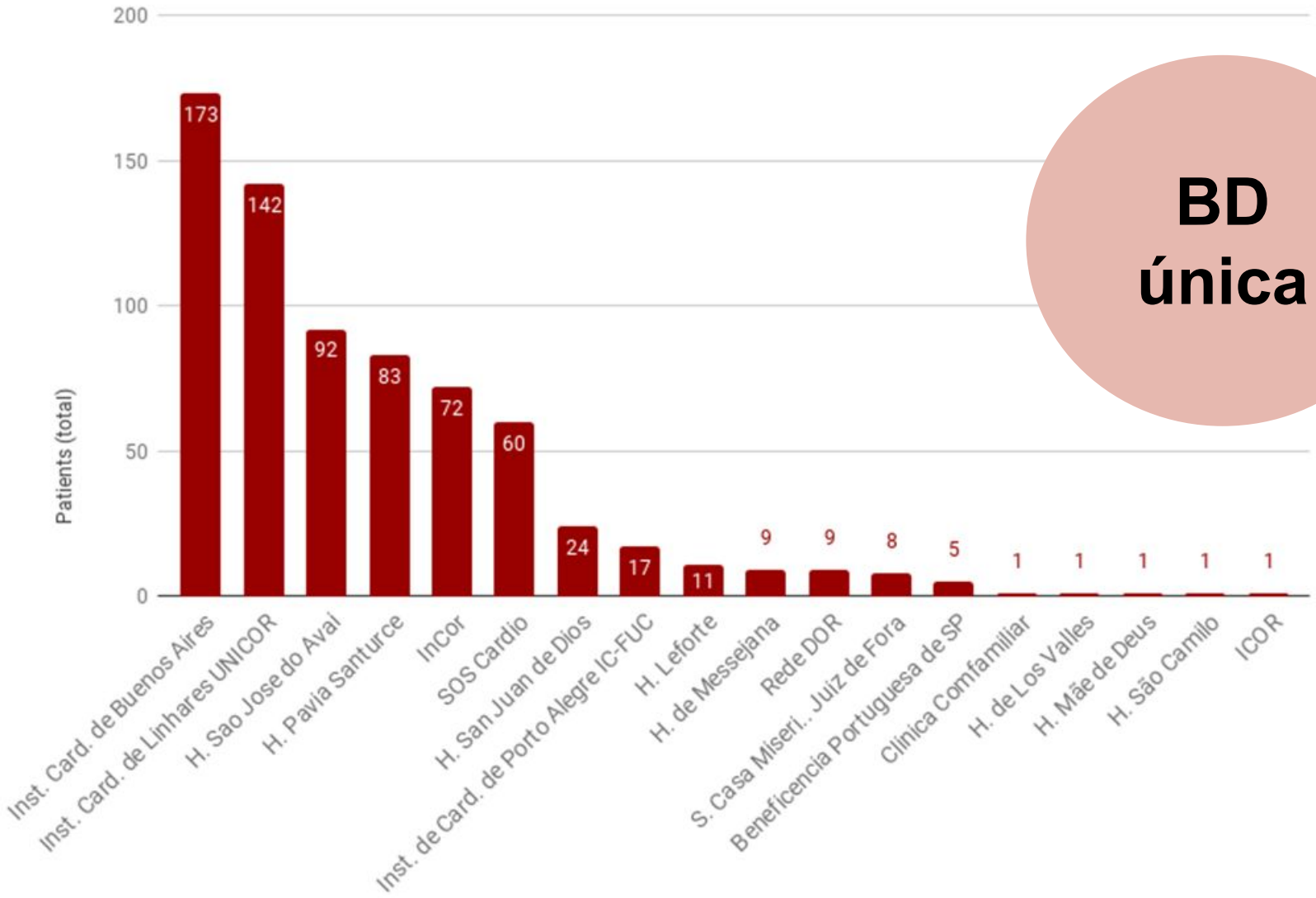
6 países

LATAM CTO Registry



18 centros

LATAM CTO Registry



BD única

REDCap

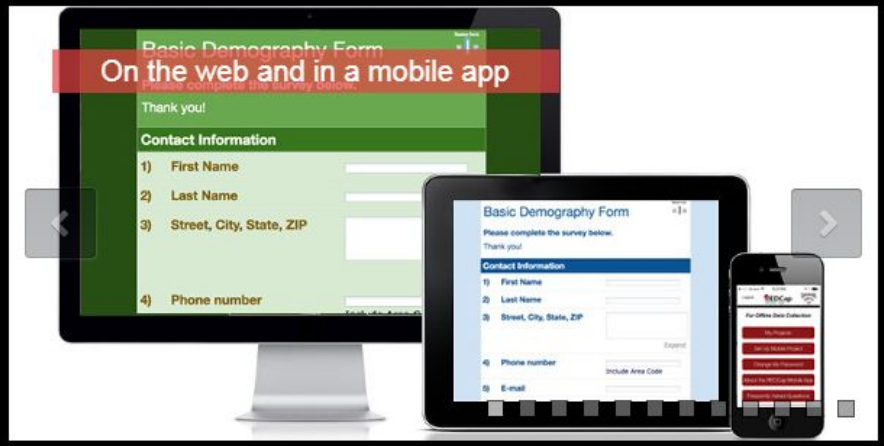
REDCap

Seguro | https://www.project-redcap.org

REDCap
Research Electronic Data Capture

Institutions 3003 | Countries 125 | Projects 572k | Users 769k | Articles 5581

ABOUT PARTNERS RESOURCES SOFTWARE



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

Institutions	Countries	Projects	Users	Articles
3003	125	572k	769k	5581

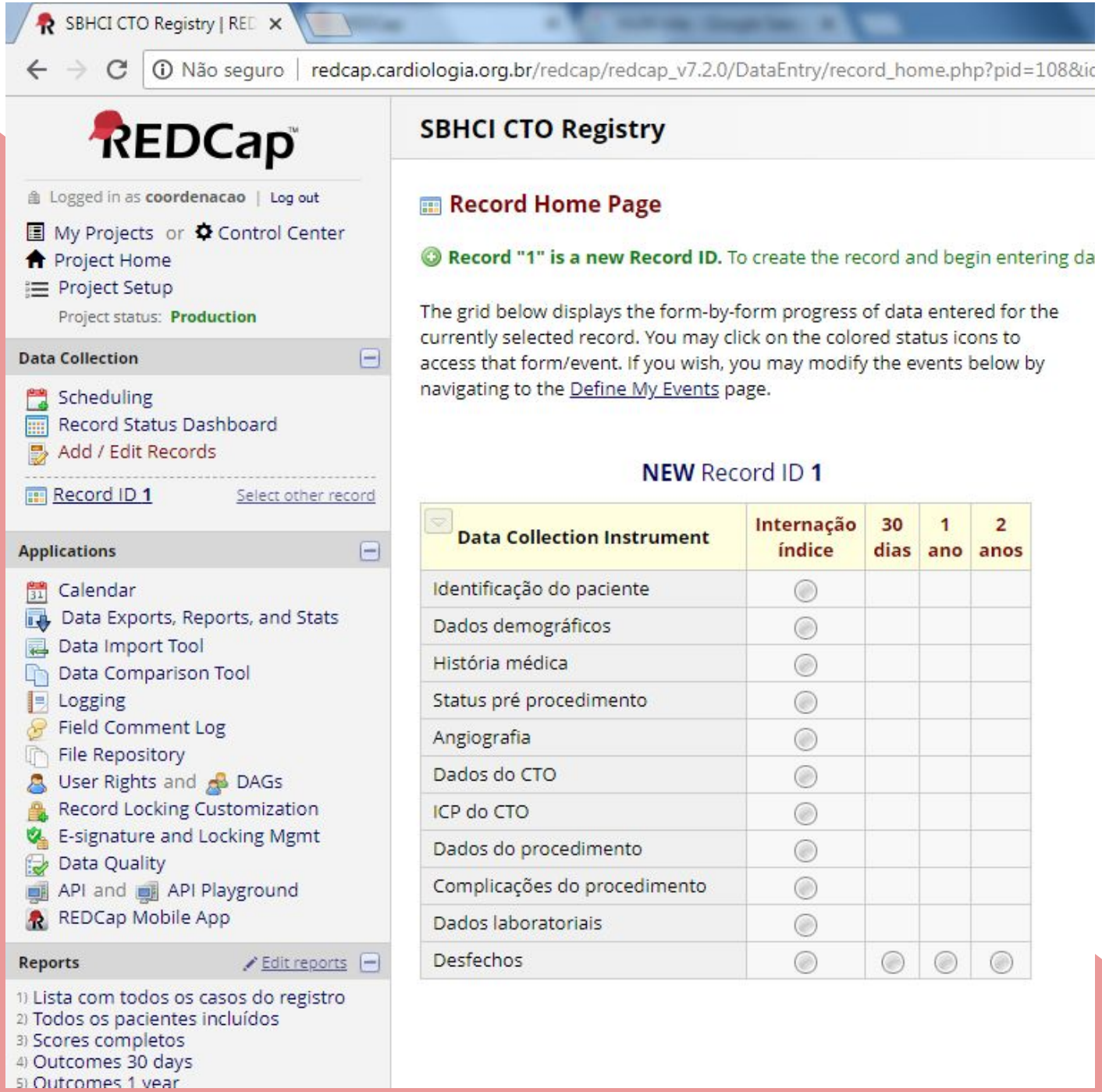
REDCap
Research Electronic Data Capture

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível


SBHCI CTO Registry | RE
Não seguro | redcap.cardiologia.org.br/redcap/redcap_v7.2.0/DataEntry/record_home.php?pid=108&ic
REDCap
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 da
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
(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

Ladies

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

REDCap
Research Electronic Data Capture

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

REDCap
Research Electronic Data Capture


Mapa
Satélite
Canadá
Baía de Hudson
Mar de Labrador
Islândia
Suécia
Finlândia
Noruega
Dinamarca
Reino Unido
Irlanda
Bielorrússia
Polônia
Alemanha
Ucrânia
França
Áustria
Romênia
Itália
Espanha
Portugal
Grécia
Turquia
Cazaquistão
Uzbequistão
Quirguistão
Turcomenistão
Síria
Iraque
Irão
Afeganistão
Paquistão
Nepal
Índia
Myan
Tunísia
Mar Mediterrâneo
Marrocos
Argélia
Líbia
Egito
Saara Ocidental
Arábia Saudita
Omã
Iémen
Golfo de Aden
Mar Arábico
Baía de Bengala
Mar das Laquedivas
Mauritânia
Mali
Níger
Chade
Sudão
Burkina Faso
Guiné
Nigéria
Gana
Golfo da Guiné
Sudão do Sul
Etiópia
Somália
Quênia
Gabão
República Democrática do Congo
Tanzânia
Angola
Zâmbia
Moçambique
Namíbia
Zimbábue
Botsuana
Madagáscar
África do Sul
Oceano Índico
Oceano Atlântico Norte
Oceano Atlântico Sul
Estados Unidos
México
Golfo do México
Cuba
Porto Rico
Guatemala
Nicarágua
Mar das Caraíbas
Venezuela
Guiana
Suriname
Colômbia
Equador
Peru
Bolívia
Paraguai
Chile
Argentina
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Termos de Uso

Design de projeto: Online ou offline

Disponibilidade: livre

Seguro e baseado na web

Rápido e flexível

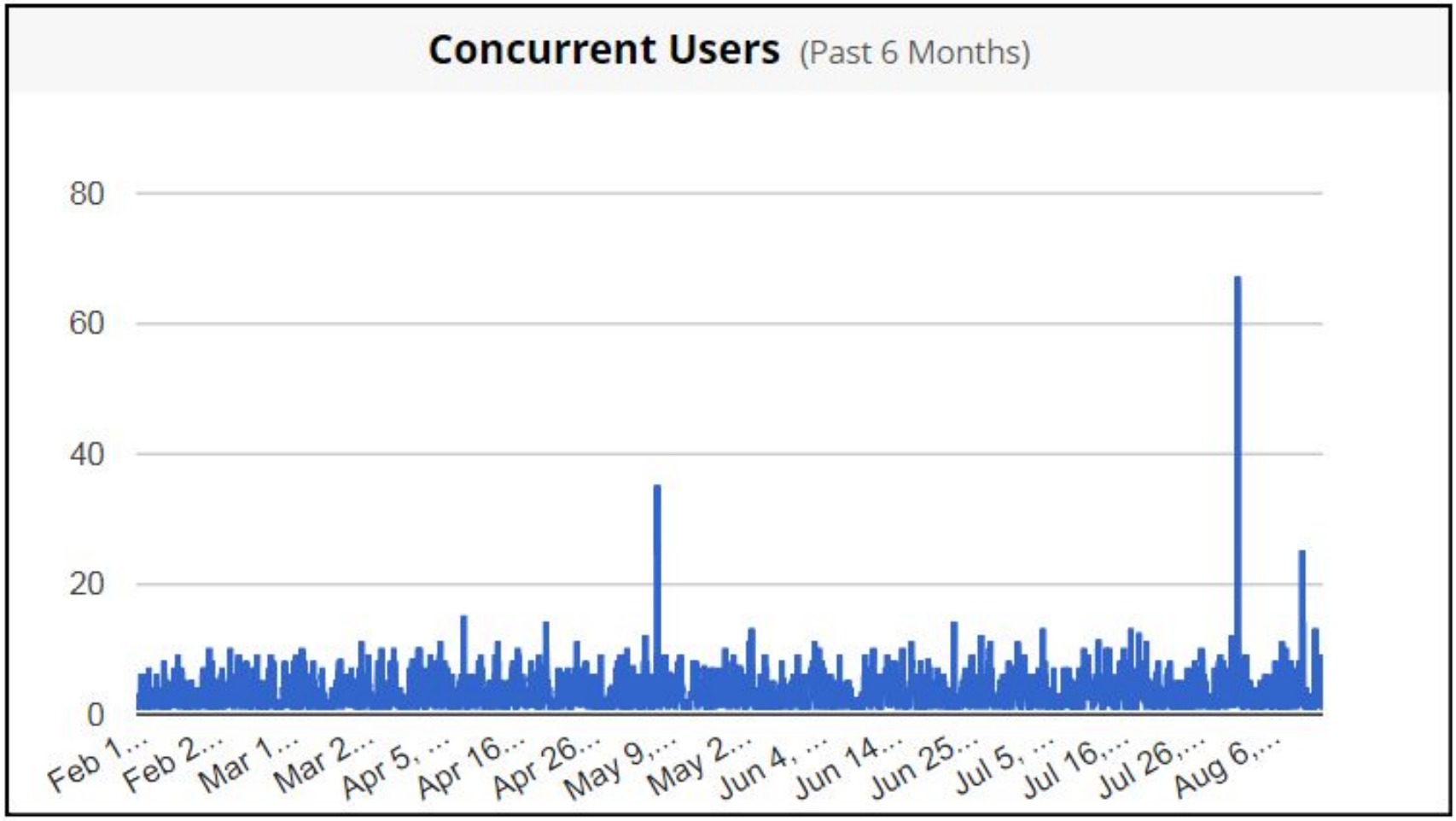
Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

REDCap
Research Electronic Data Capture


Concurrent Users (Past 6 Months)
80
60
40
20
0
Feb 1...
Feb 2...
Mar 1...
Mar 2...
Apr 5, ...
Apr 16...
Apr 26...
May 9,...
May 2...
Jun 4, ...
Jun 14...
Jun 25...
Jul 5, ...
Jul 16,...
Jul 26,...
Aug 6,...

Acesso múltiplo

Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

Ladies

Acesso múltiplo

Utilização autônoma

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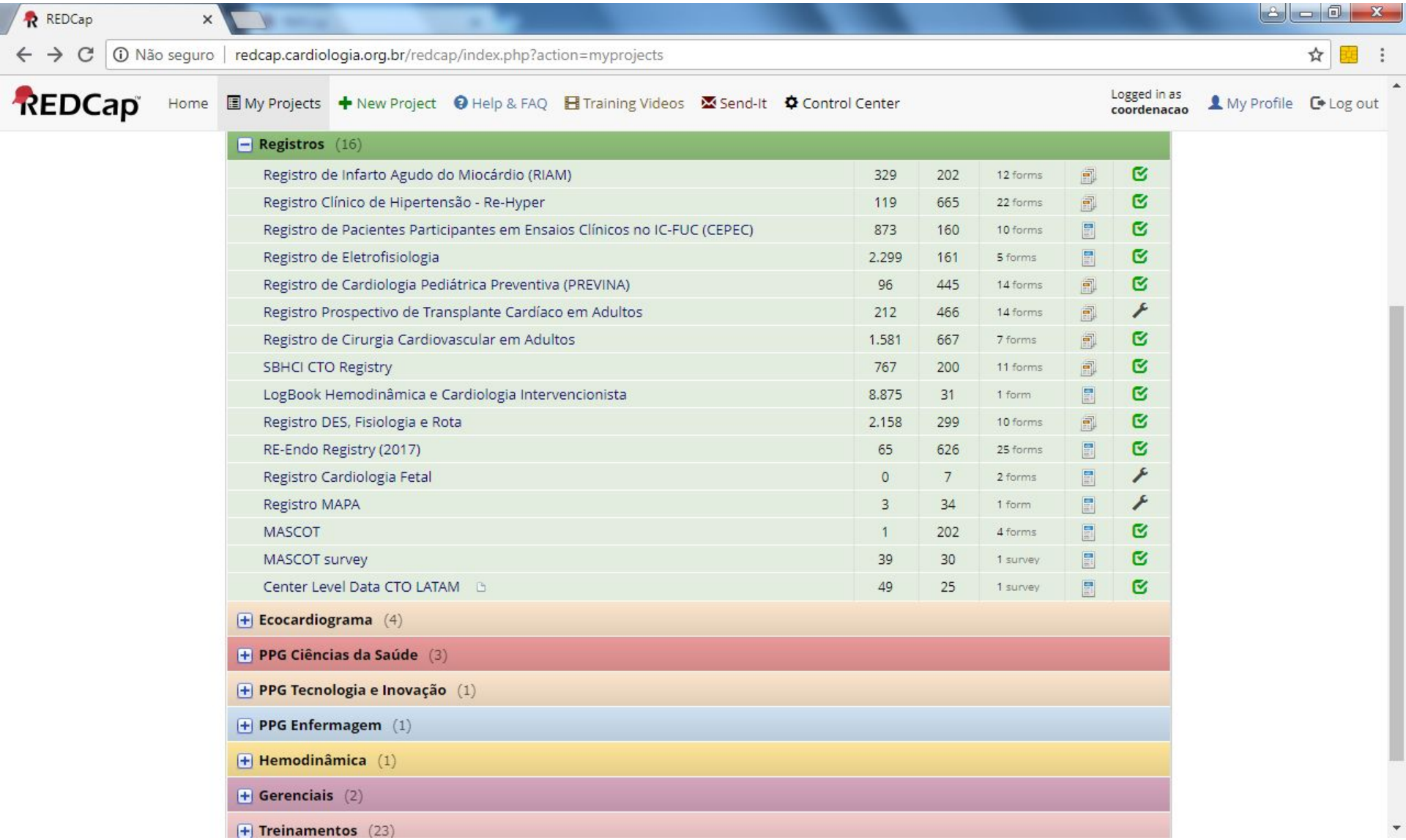
Procedimentos automatizados de exportação

REDCap
Research Electronic Data Capture


REDCap
Não seguro | redcap.cardiologia.org.br/redcap/index.php?action=myprojects
REDCap
Home
My Projects
New Project
Help & FAQ
Training Videos
Send-It
Control Center
Logged in as coordenacao
My Profile
Log out
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)

Ladies

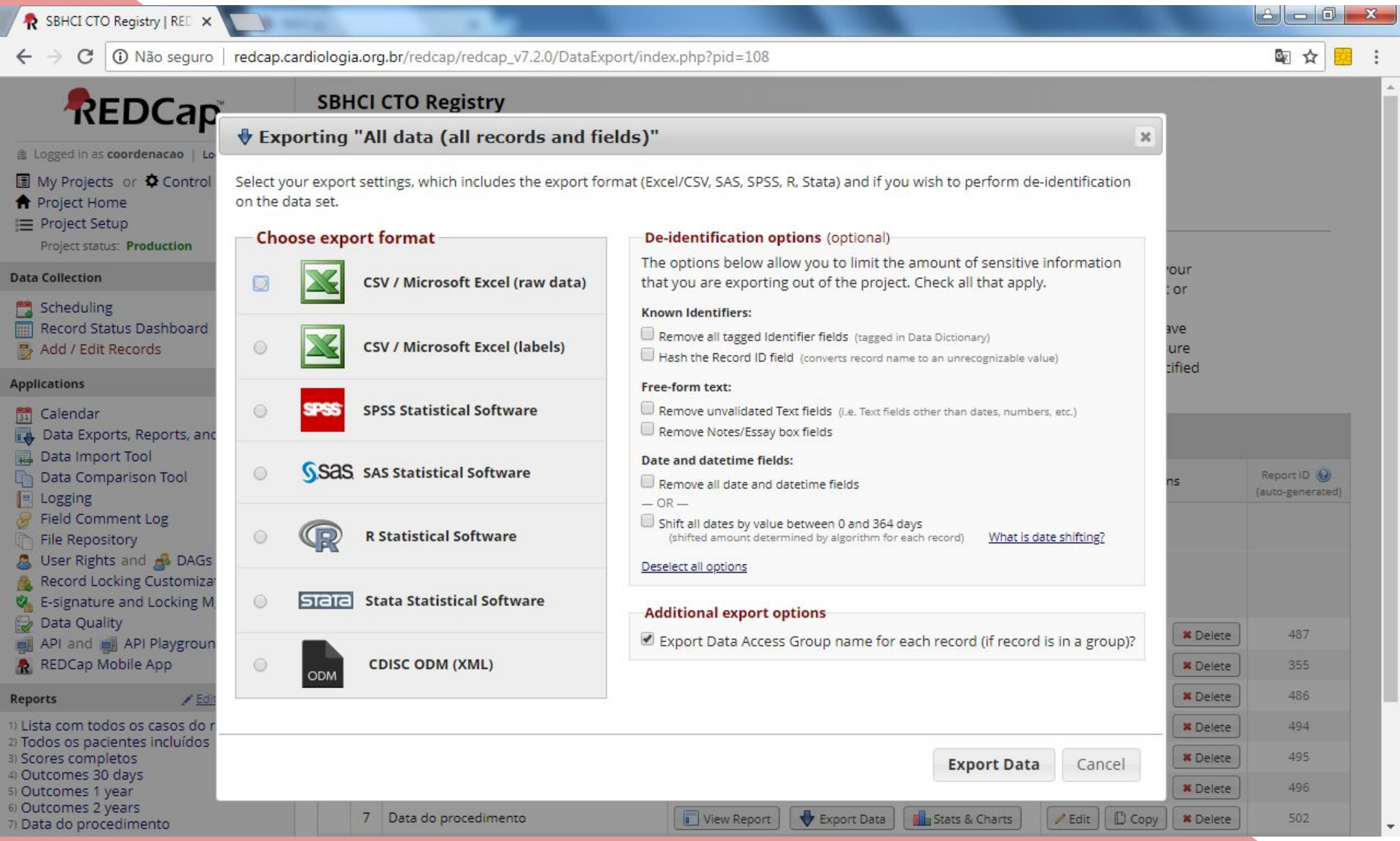
Acesso múltiplo

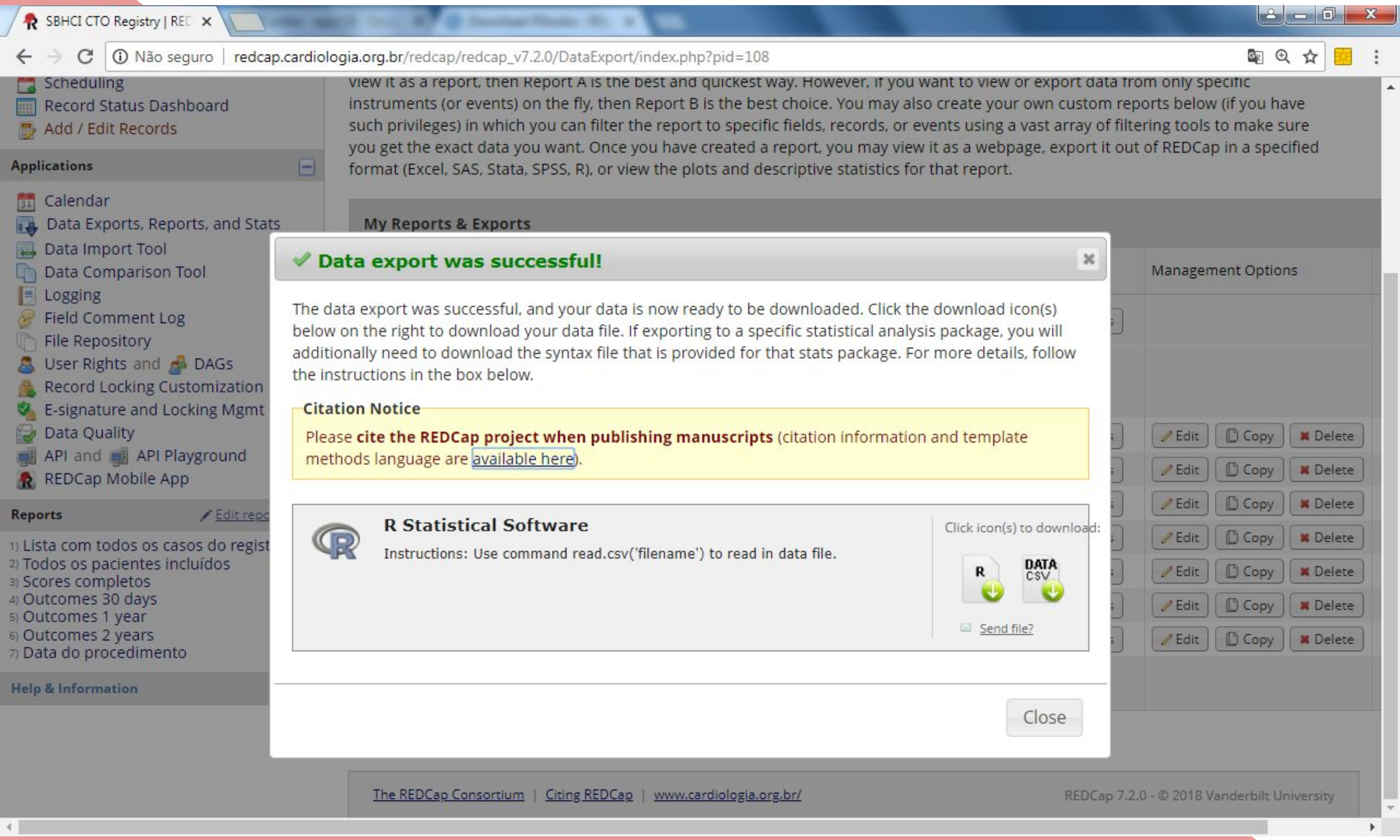
Utilização autônoma

Totalmente personalizável

Procedimentos automatizados de exportação

REDCap
Research Electronic Data Capture


SBHCI CTO Registry | RED
Não seguro | redcap.cardiologia.org.br/redcap/redcap_v7.2.0/DataExport/index.php?pid=108
REDCap
SBHCI CTO Registry
Logged in as coordenacao
My Projects or Control
Project Home
Project Setup
Project status: Production
Data Collection
Scheduling
Record Status Dashboard
Add / Edit Records
Applications
Calendar
Data Exports, Reports, and
Data Import Tool
Data Comparison Tool
Logging
Field Comment Log
File Repository
User Rights and DAGs
Record Locking Customiza
E-signature and Locking M
Data Quality
API and API Playgroun
REDCap Mobile App
Reports
1) Lista com todos os casos do r
2) Todos os pacientes incluídos
3) Scores completos
4) Outcomes 30 days
5) Outcomes 1 year
6) Outcomes 2 years
7) Data do procedimento
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
Report ID (auto-generated)
Delete
487
355
486
494
495
496
502
7 Data do procedimento
View Report
Export Data
Stats & Charts
Edit
Copy
Delete


SBHCI CTO Registry | RED
Não seguro | redcap.cardiologia.org.br/redcap/redcap_v7.2.0/DataExport/index.php?pid=108
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
E-signature and Locking Mgmt
Data Quality
API and API Playground
REDCap Mobile App
Reports
Edit repo
1) Lista com todos os casos do regist
2) Todos os pacientes incluídos
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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
Edit
Copy
Delete
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:
R
DATA CSV
Send file?
Close
The REDCap Consortium | Citing REDCap | www.cardiologia.org.br/
REDCap 7.2.0 - © 2018 Vanderbilt University

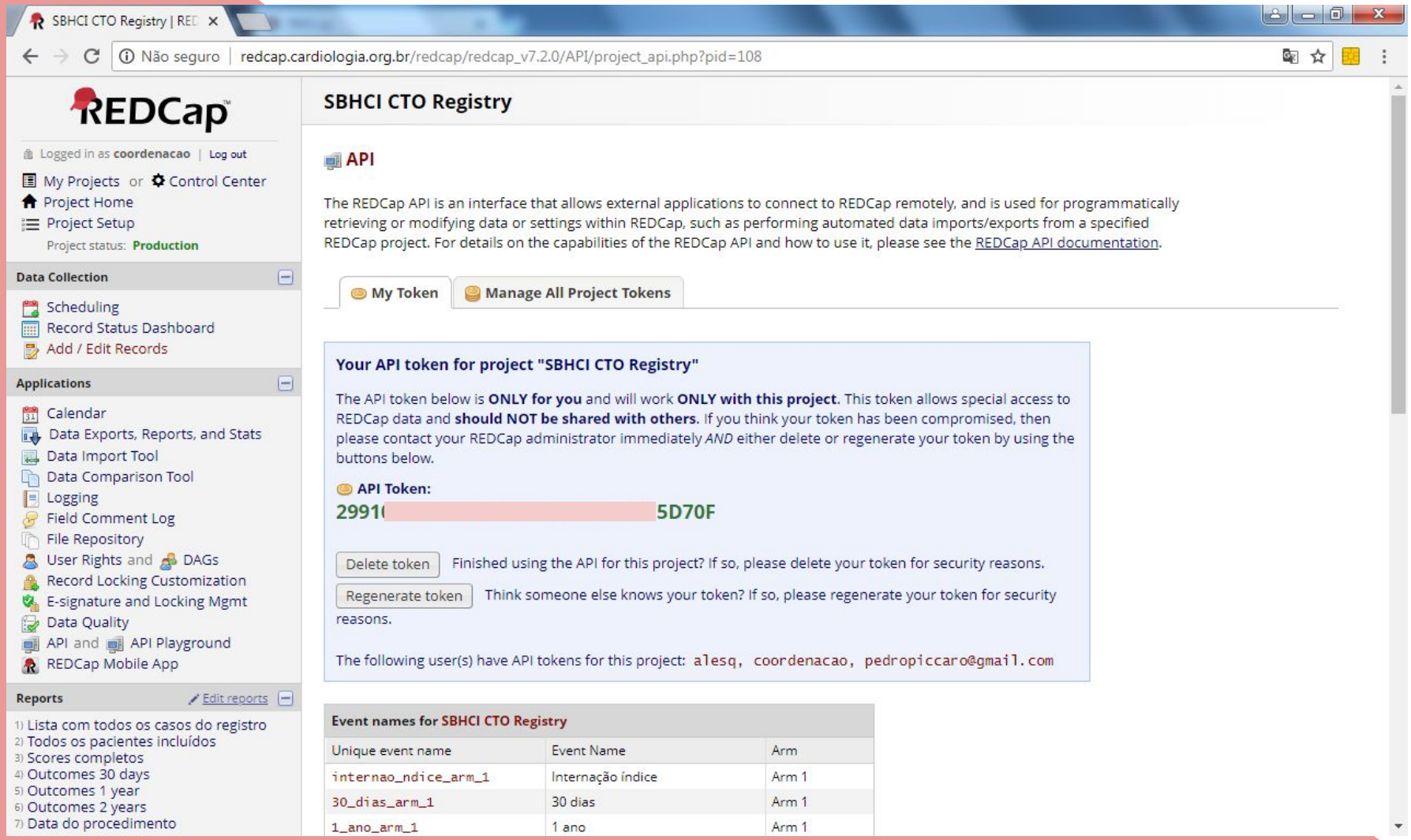
API = 'Application Programming Interface'

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'



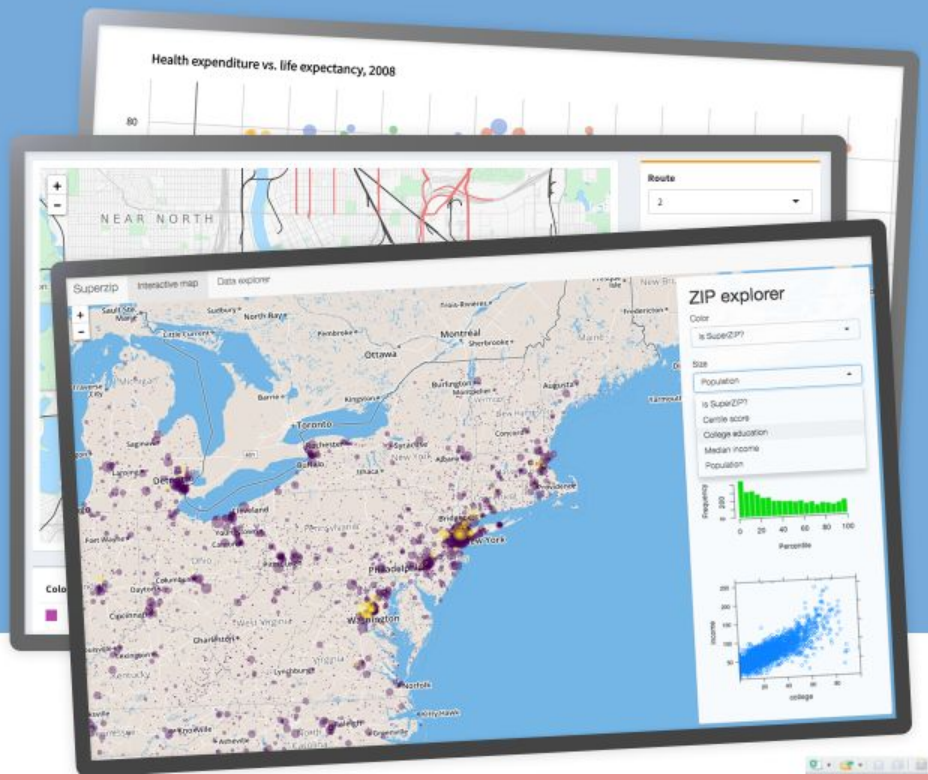
R

Shiny

Seguro | https://shiny.rstudio.com

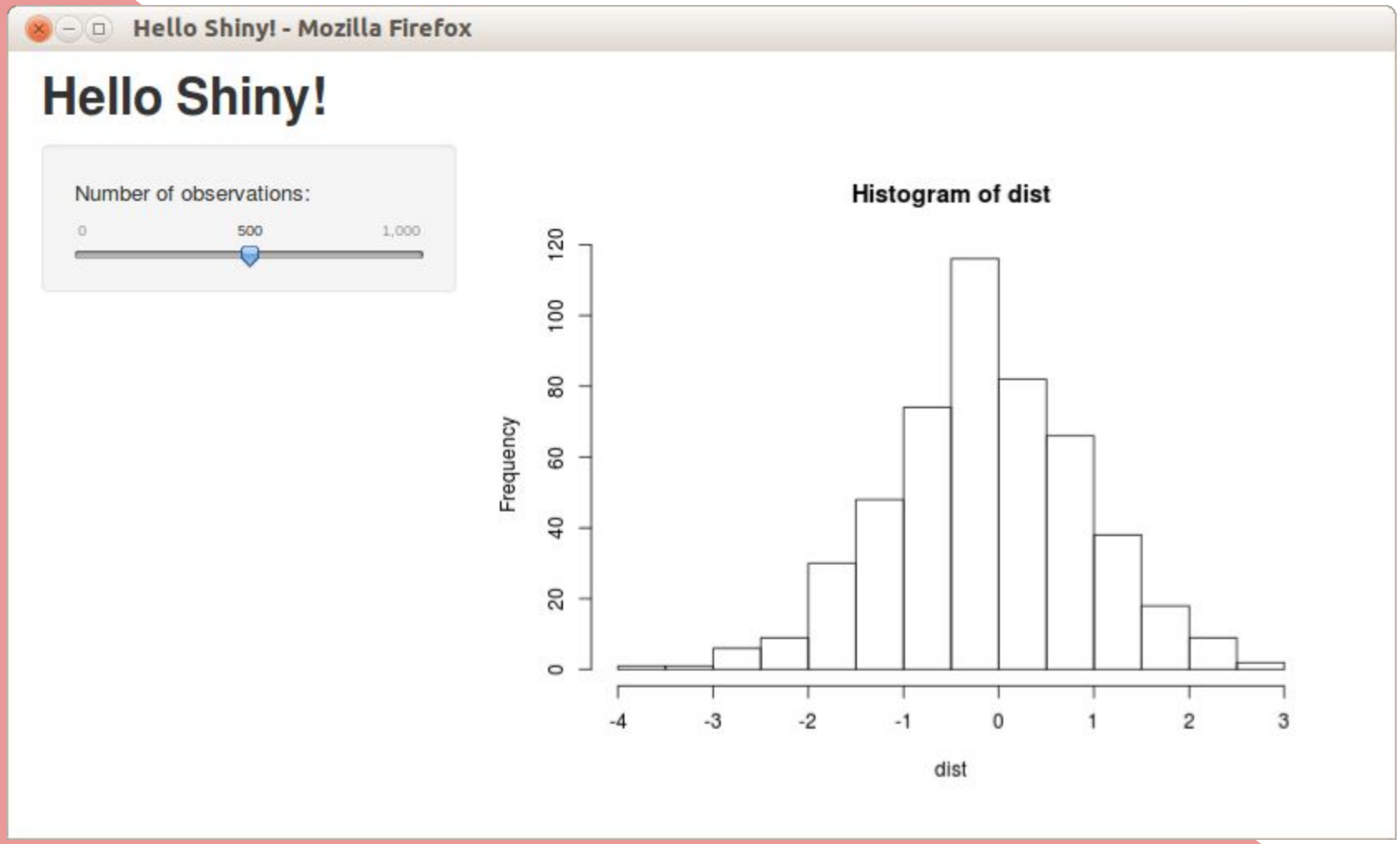
Shiny from RStudio

Get Started Gallery Articles Reference Deploy Help Contribute



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! - Mozilla Firefox
Hello Shiny!
Number of observations:
0
500
1,000
Histogram of dist
Frequency
0
20
40
60
80
100
120
-4
-3
-2
-1
0
1
2
3
dist

Movie explorer

Filter

Minimum number of reviews on Rotten Tomatoes

10 80 300

Year released

1,940 1,970 2,014

Minimum number of Oscar wins (all categories)

0 4

Dollars at Box Office (millions)

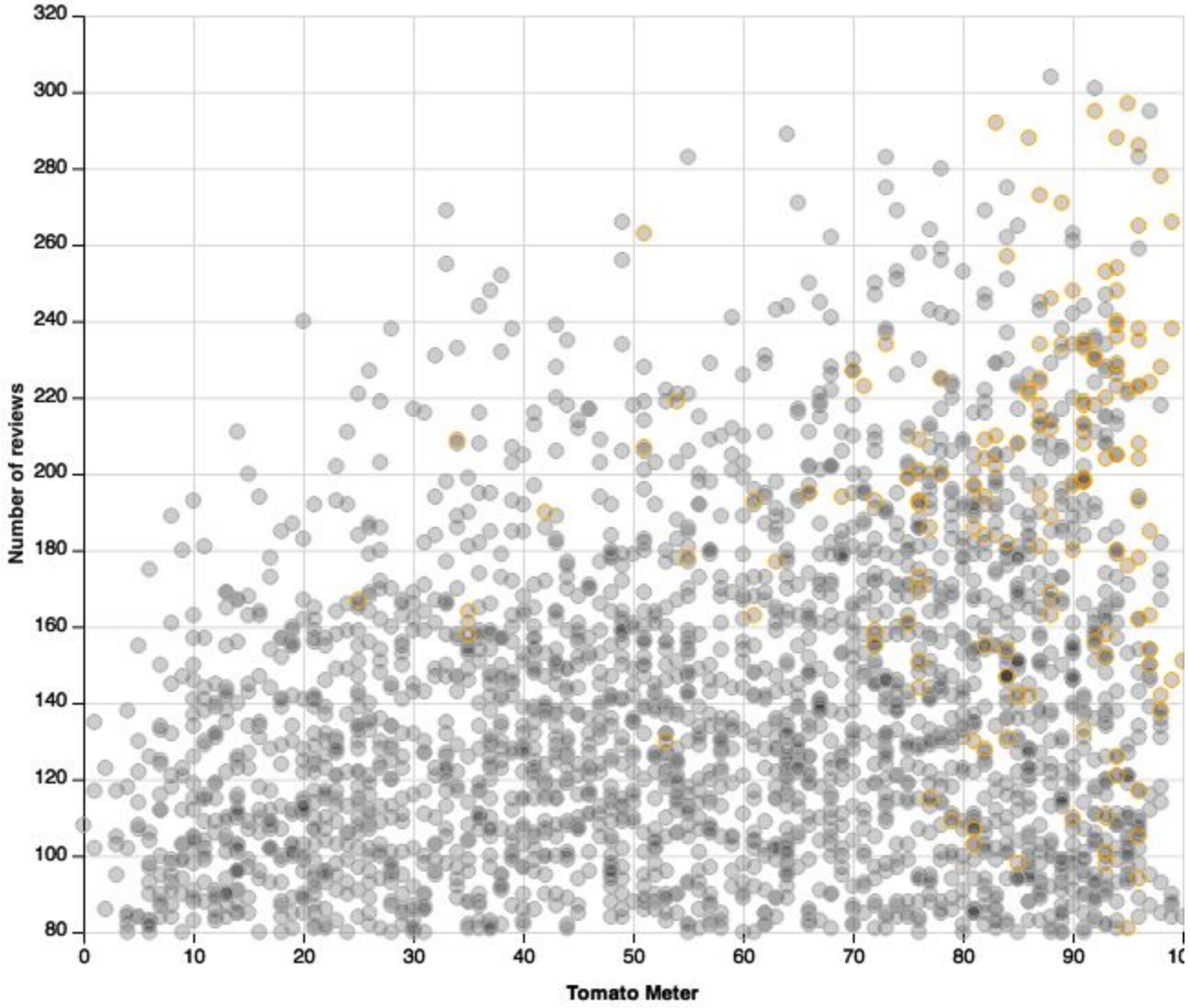
0 800

Genre (a movie can have multiple genres)

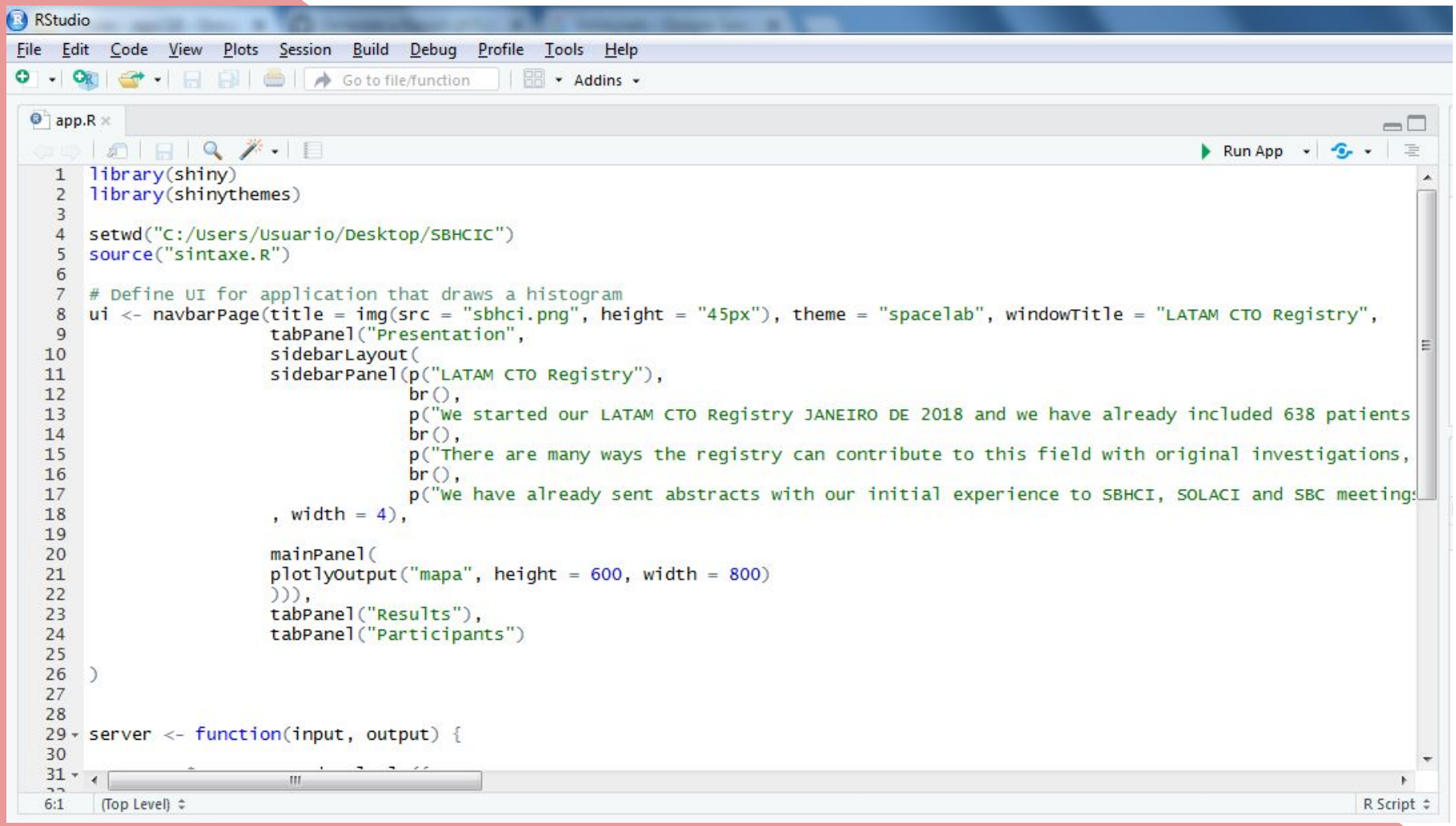
All

X-axis variable

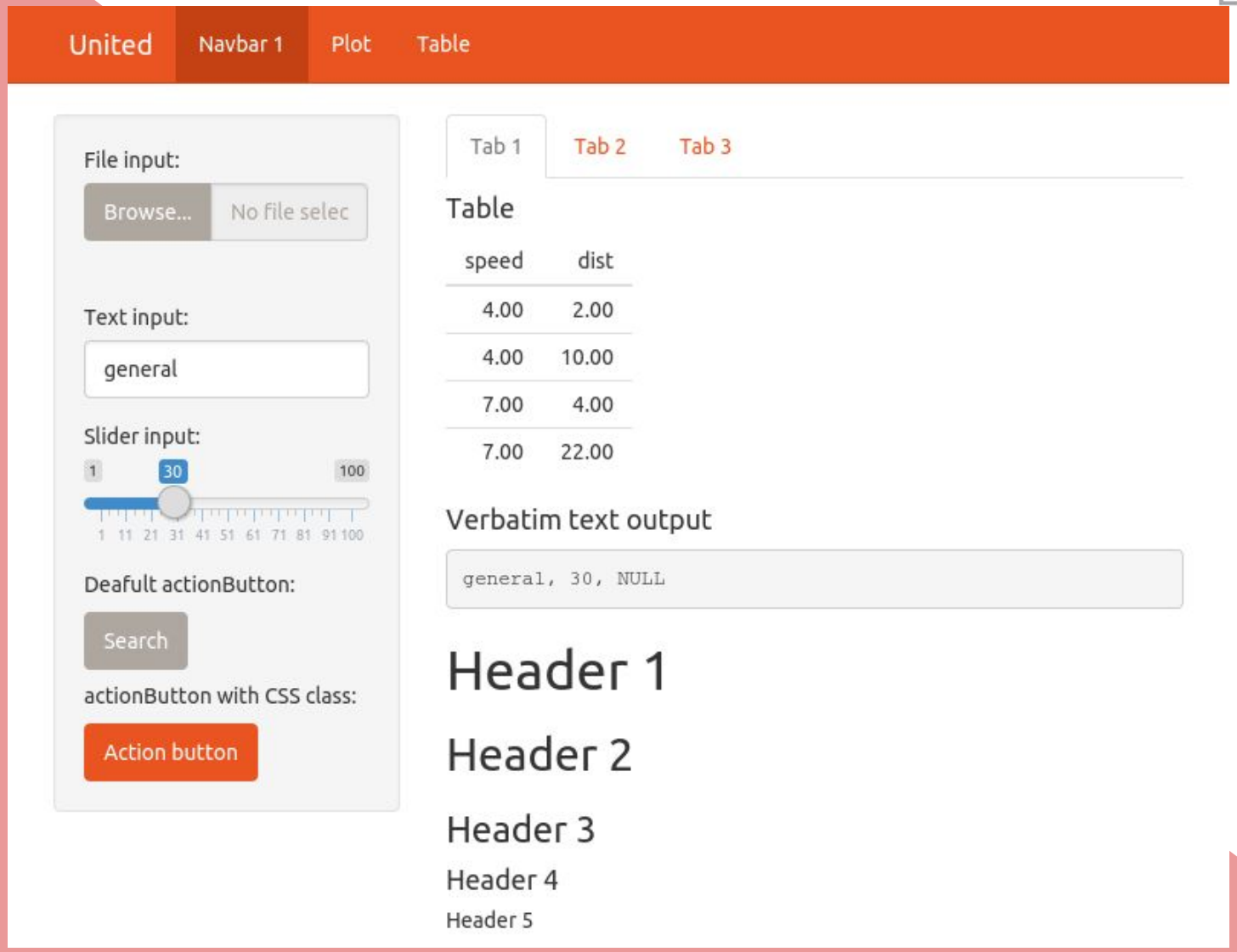
Tomato Meter



Programação



Escolha do tema



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

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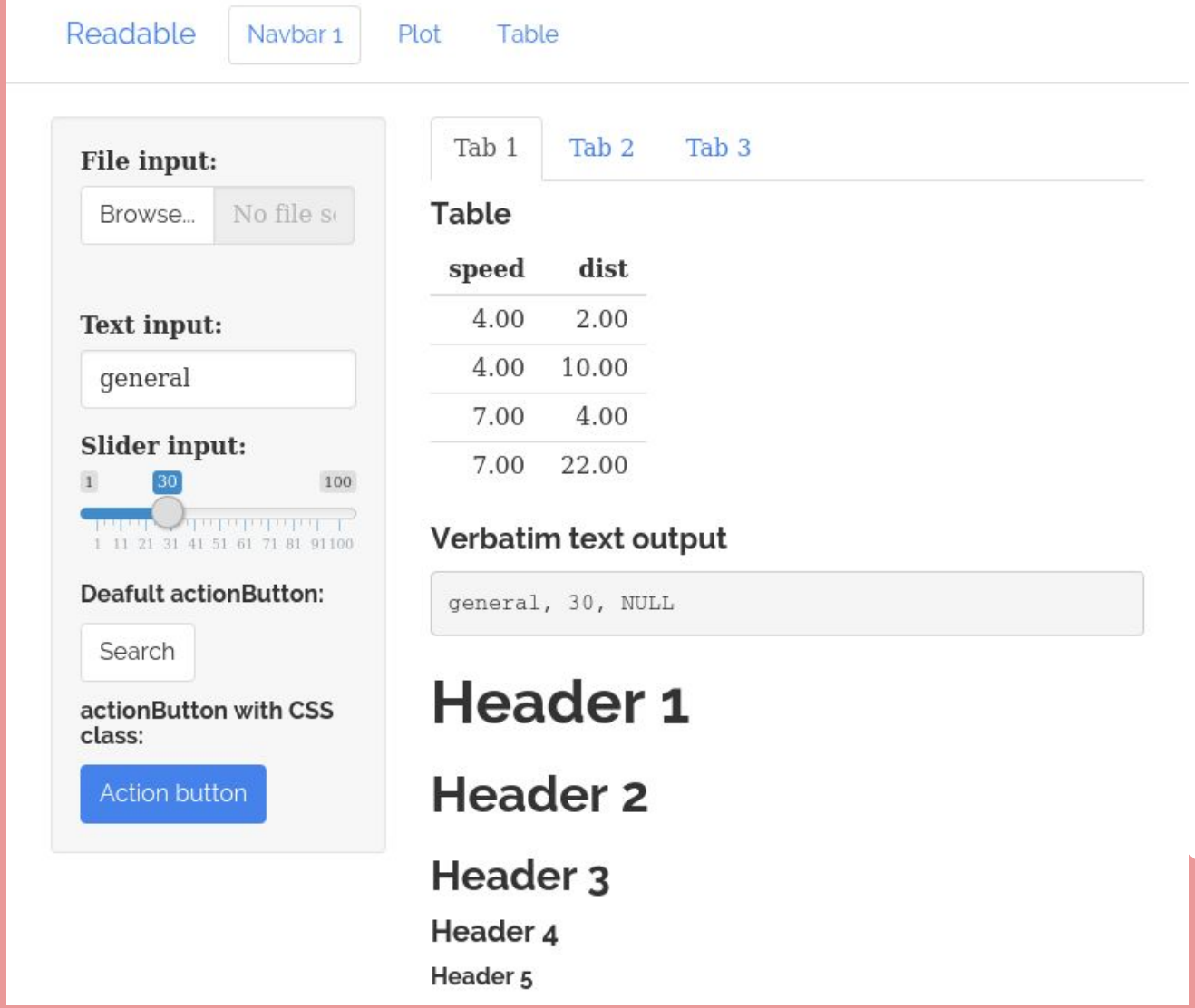

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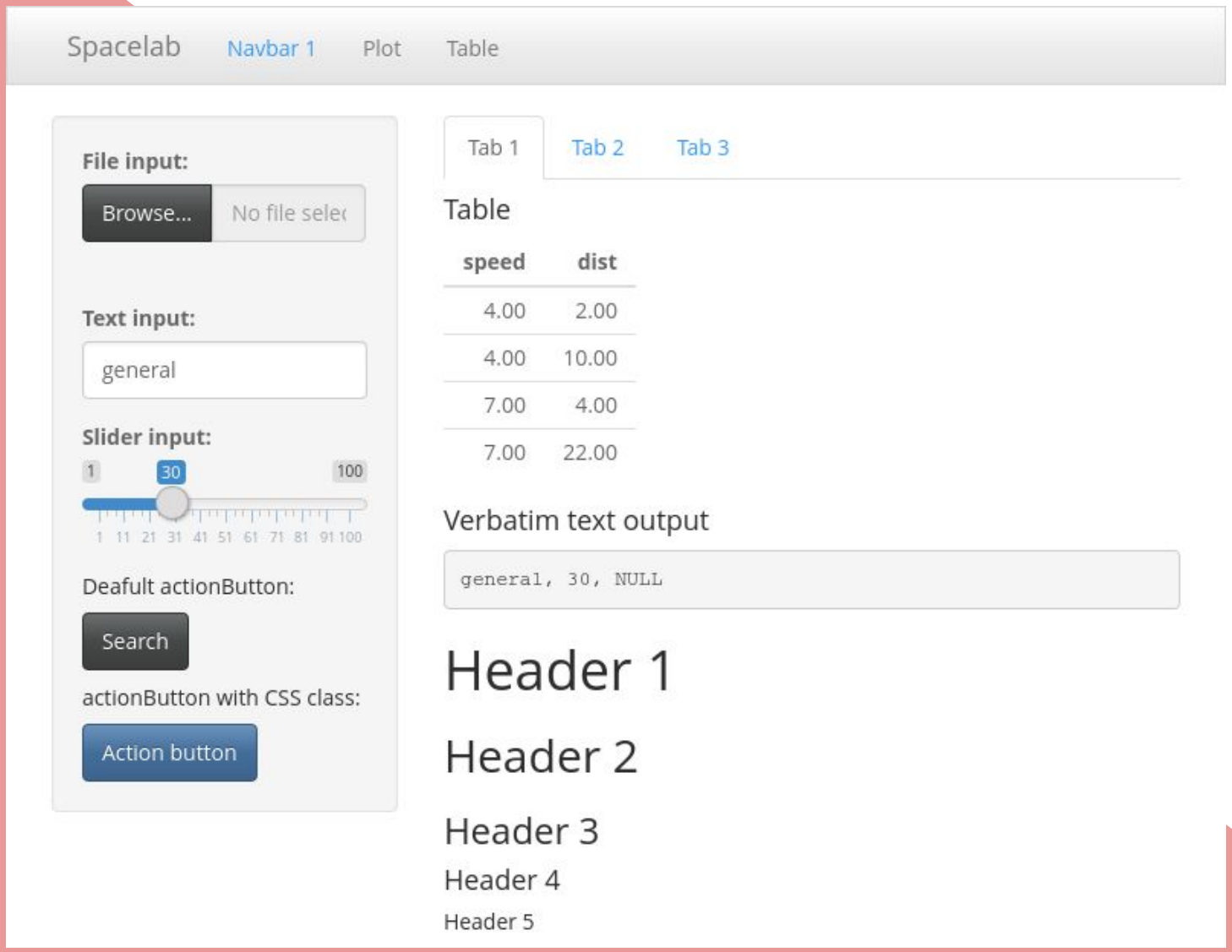
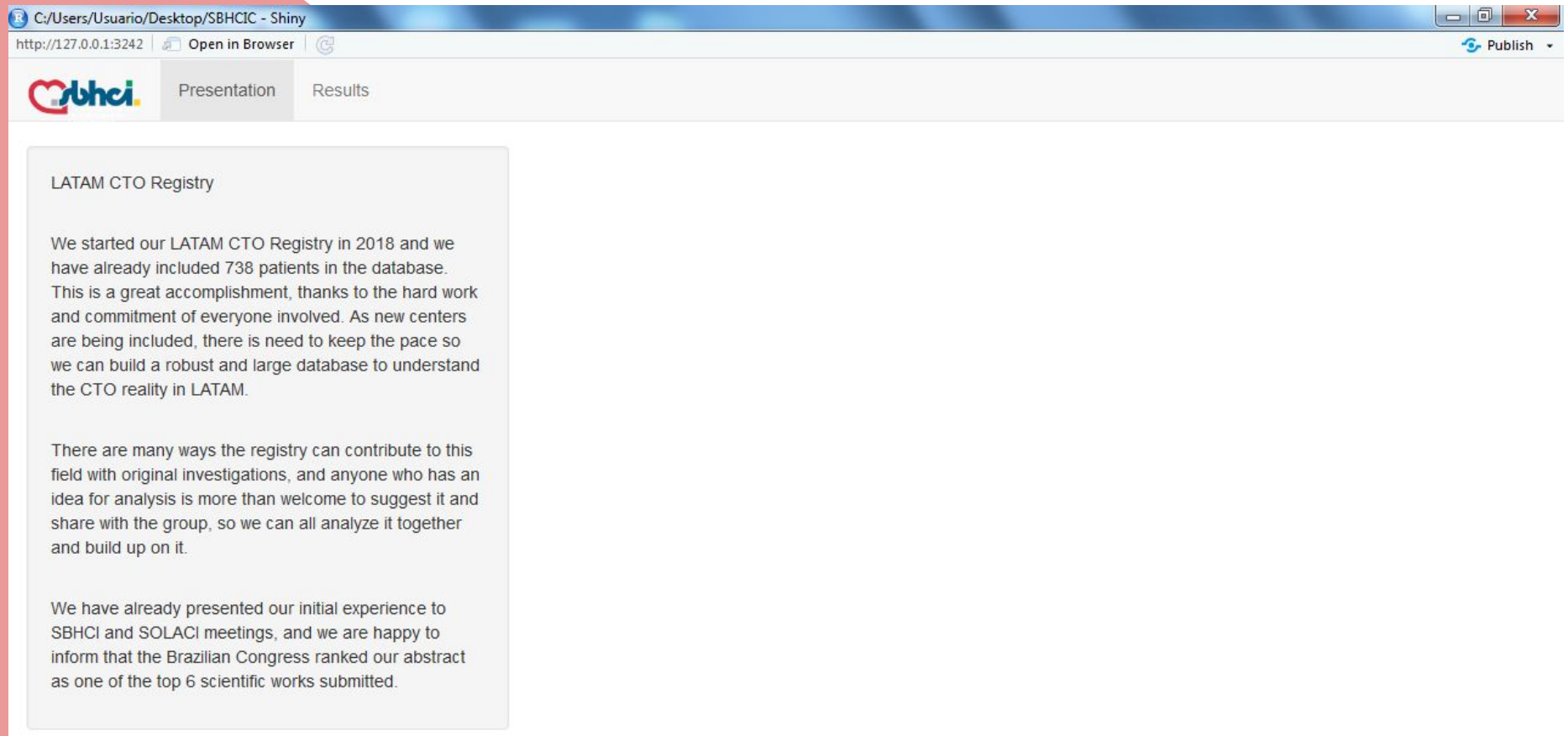
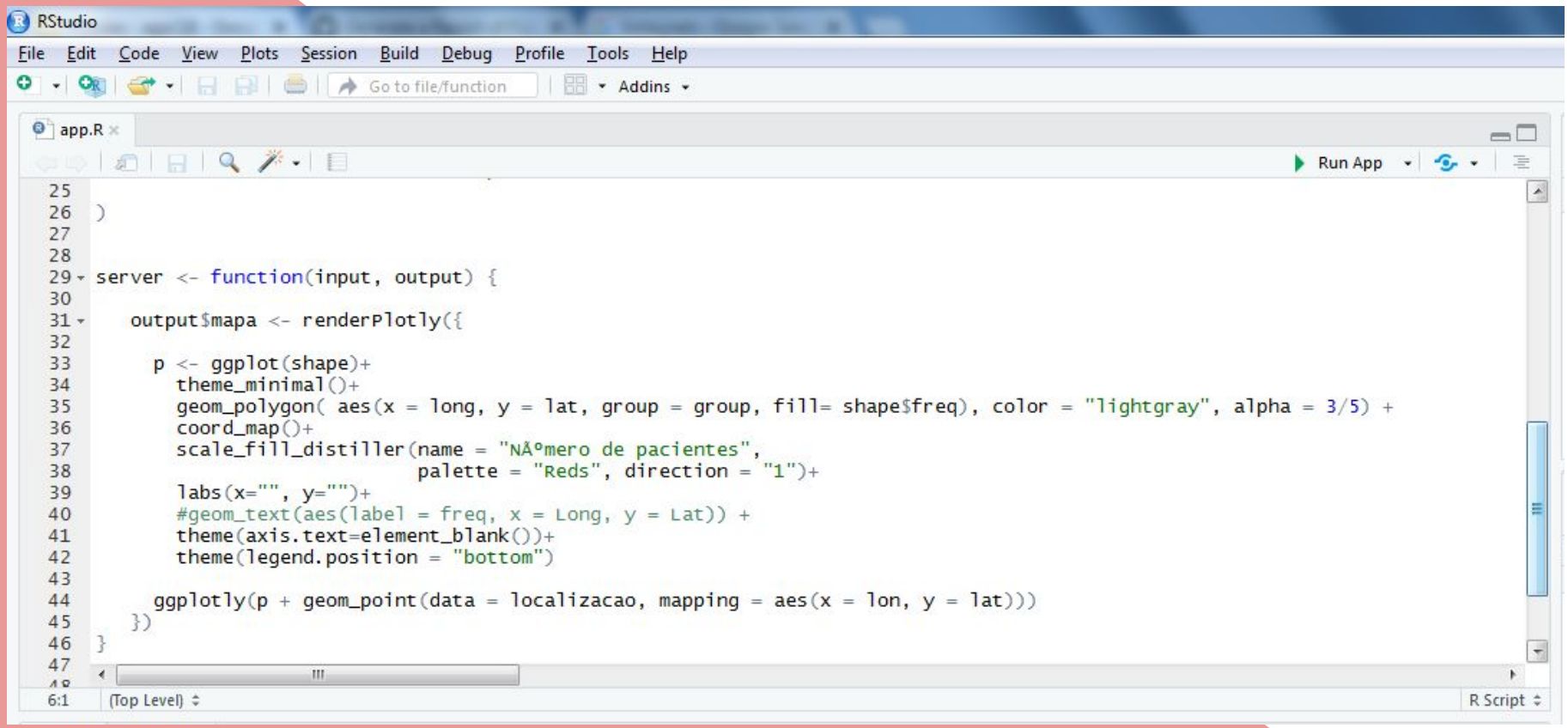


https://rstudio.github.io/shinythemes/

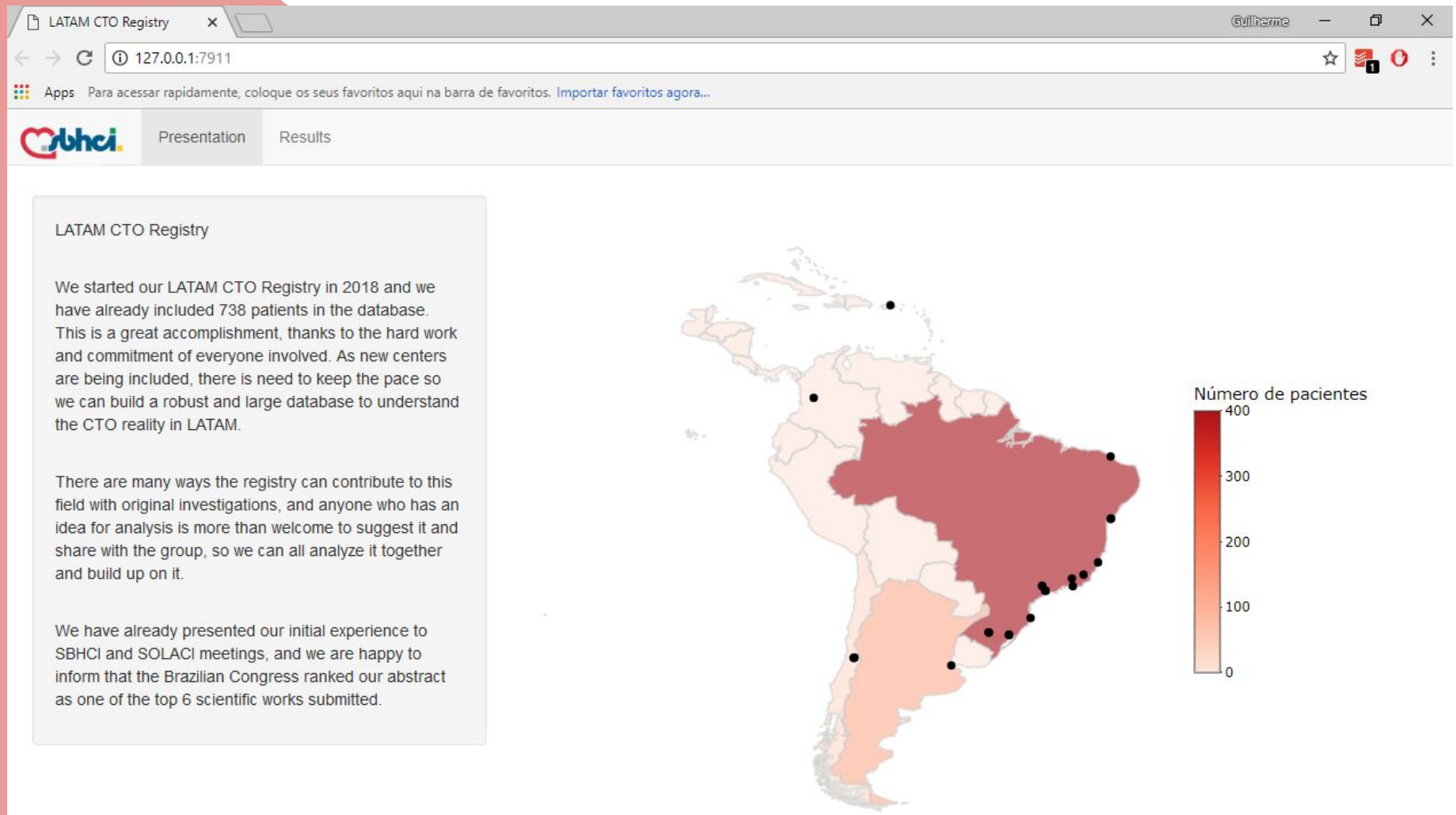
Componentes da aplicação



Programação



Componentes da aplicação



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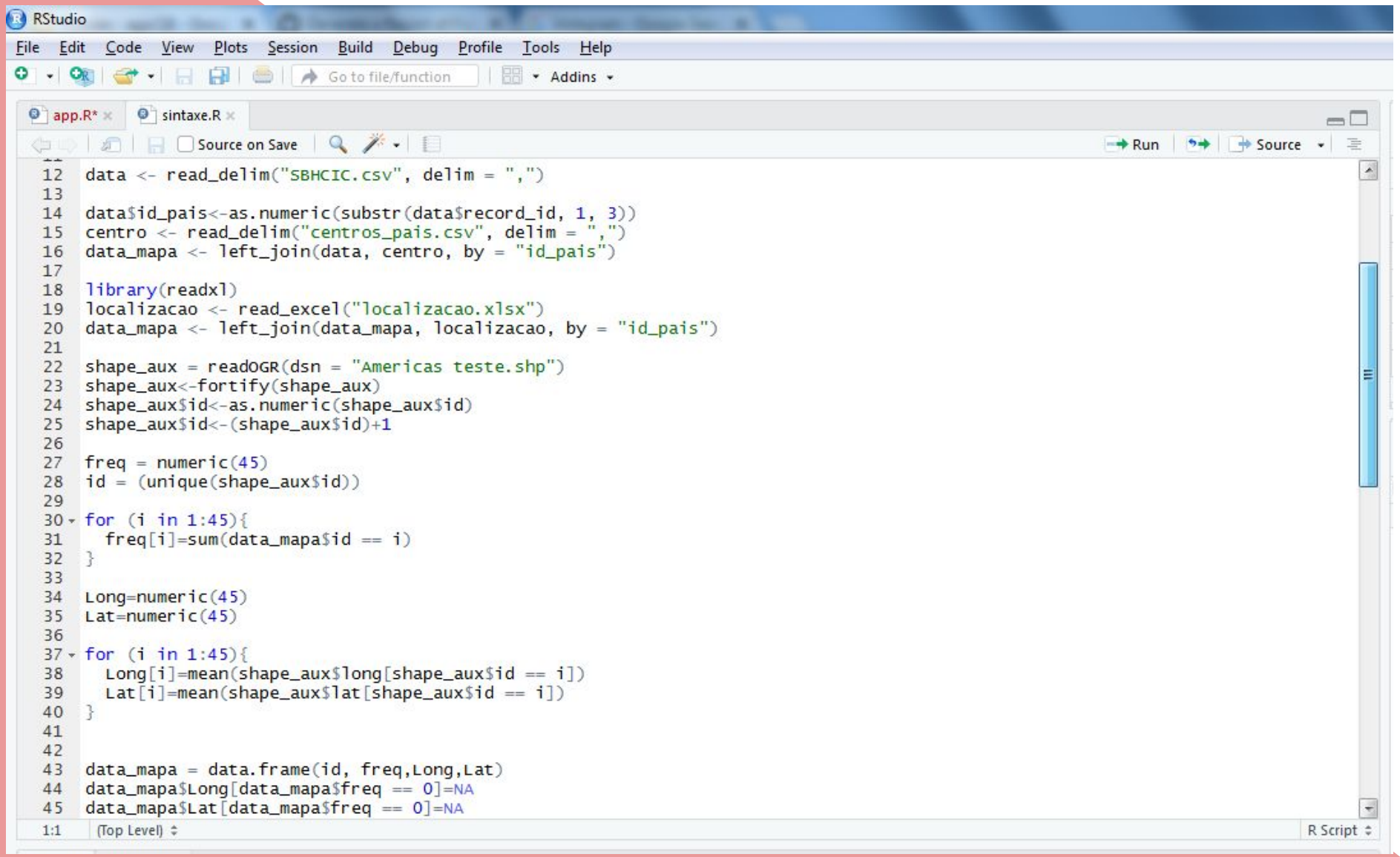

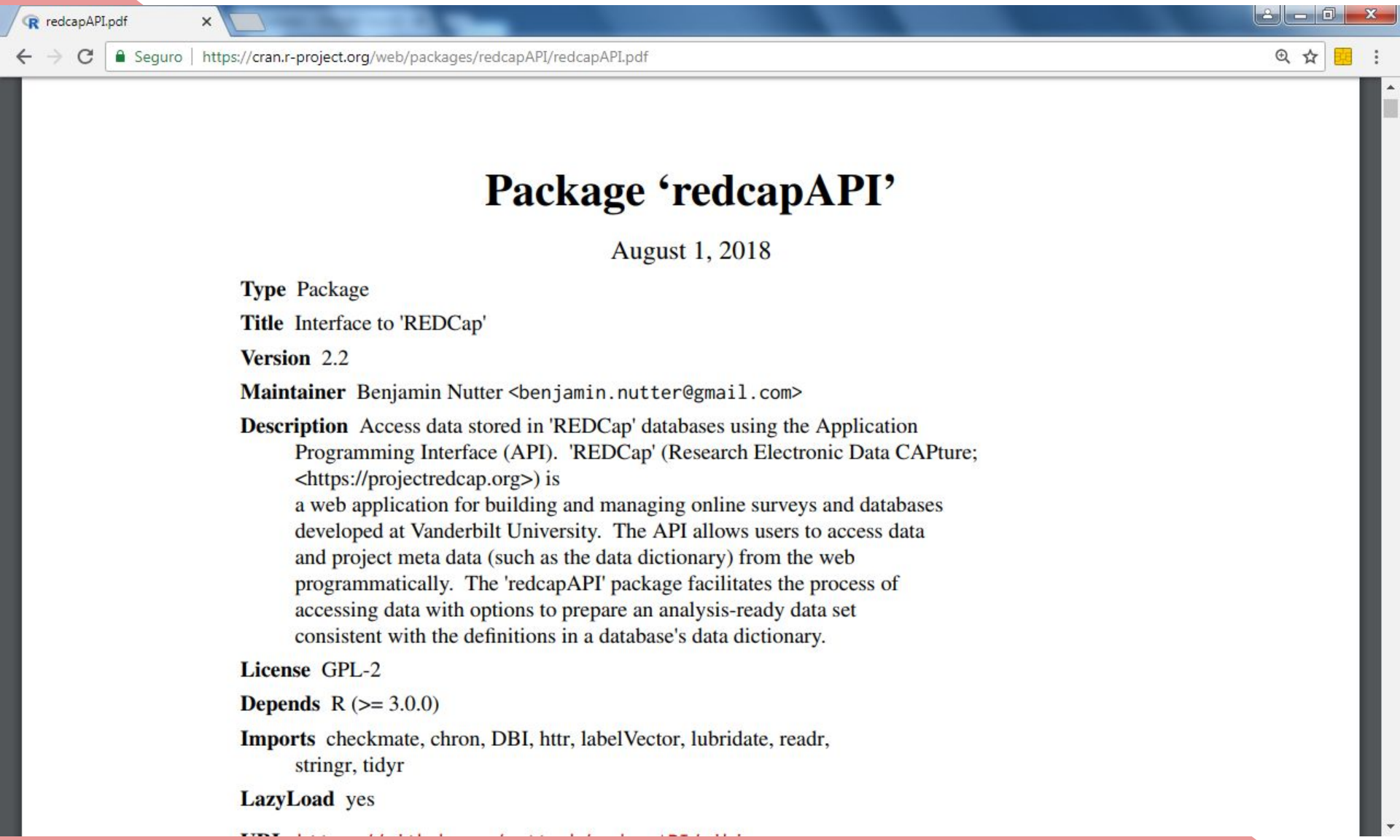

Package 'redcapAPI'

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

Ladies

Registros Clínicos

REDCap: API

R: Shiny

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

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