



# FIRST LATIN AMERICAN & BRAZILIAN REDCapCon

APRIL 26-27, 2018 - SÃO PAULO - HOSPITAL SÍRIO LIBANÊS



### Bienvenido. Welcome. Seja bem-vindo.

More than an honor, it is a great pleasure to have you at the First Latin American & Brazilian REDCap Conference - REDCapCon.

In our conference, you will be exposed to a great deal of information, exchange of ideas, and diverse opinions about the incorporation of technological solutions to the scientific research world. Experts, researchers, teachers, administrators, students, colleagues and professionals from different countries will be gathering together with one goal: make the REDCap Community increasingly relevant to the challenges of science.

Seize this opportunity to the fullest. Increase your network. Make new friends. Enjoy the hospitality of São Paulo.

Brazilian REDCap Consortium hopes that the REDCapCon will be an empowering experience both for your personal and professional life.

Thank you for being here.

The Organizing Committee









































































### **Program Committee - International**

**Paul Harris** 

(Vanderbilt University, USA)

**Rob Taylor** 

(Vanderbilt University, USA)

**Brenda Minor** 

(Vanderbilt University, USA)

Stephany Duda

(Vanderbilt University, USA)

Ceci Chamorro

(Duke University, USA)

Linda Carlin

(University of Colorado, USA)

**Mark Munsell** 

(M.D. Anderson Cancer Center, USA)

Joseph Thomas

(M.D. Anderson Cancer Center, USA)

Bernard A. LaSalle

(University of Utah, USA)

Bas de Veer

(University os Washington, USA)

Victor Espinosa

(Vancouver Island Health Authority, Canada)

Daniele Vicari

(University of Sydney, Australia)

Cristobal Carvajal

(Clinica Alemana, Chile)

Mariano de Stefano Parma

(Fundacion Huesped, Argentina)



### Program Committee – Local (Brazil)

### Kátia Regina da Silva

(Universidade de São Paulo, SP)

### Roberto Costa

(Universidade de São Paulo, SP)

### **Jacson Barros**

(Hospital das Clínicas da FMUSP, SP)

### **Eduardo Abrantes**

(Hospital Sírio Libanês, SP)

### José Eduardo Krieger

(Universidade de São Paulo, SP)

### José Otávio Auler Jr.

(Universidade de São Paulo, SP)

### Fábio Jatene

(Universidade de São Paulo, SP)

### **Eduardo Massad**

(Universidade de São Paulo, SP)

### Ricardo dos Reis

(Hospital de Câncer de Barretos, SP)

### Fernando Colugnati

(Universidade Federal de Juiz de Fora, MG)

### Fabio Carmona

(Faculdade de Medicina de Ribeirão Preto, USP)

### Luciano Kalabric Silva

(FIOCRUZ, BA)



### **Organizing Committee**

Roberto Costa

(Universidade de São Paulo, SP)

Kátia Regina da Silva

(Universidade de São Paulo, SP)

**Jacson Barros** 

(Hospital das Clínicas da FMUSP, SP)

Fernando Shiguemichi

(REDCap-Brasil)

Marcia Mitie Nagumo

(REDCap-Brasil)

Jéssica Moretto Crivelari

(REDCap-Brasil)

Luiz Felipe Pinho Moreira

(Universidade de São Paulo, SP)



### **General Information**

### Registration

Registration and Conference badges pick-up will be available from April 26, 2018 from 7:30am in the main entrance of Instituto Sírio-Libanês de Ensino e Pesquisa (IEP), and is valid for both days of the Conference.

### **Mobile Application**

The Conference program as well as access to all presentation and lecture's PDF will be available at App REDCapCon BR&LA. Please visit Apple App Store or Google Play Store to download it for free.





### Internet

The Instituto Sirio-Libanes de Ensino e Pesquisa (IEP) has wireless internet. Username and login will be available on the day of the Conference for all visitors and guests.



& BRAZILIAN REDCapCon

### **Dress code**

The Conference dress code is casual. It is recommended to keep in mind that the environment is climatized, so it is important to bring a light sweater.

### **Hotel Address Information**

Instituto de Ensino e Pesquisa – Hospital Sírio Libanês

R. Prof. Daher Cutait, 69 - Bela Vista, São Paulo - SP, 01308-060

### **Hotel Renaissance**

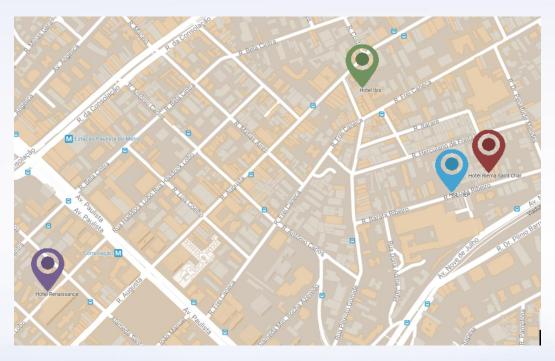
Alameda Santos, 2233 - Cerqueira César, São Paulo - SP, 01419-002 1,4 km de distância - 18 minutos andando

### Hotel Ibis - Frei Caneca

R. Frei Caneca, 826 - Consolação, São Paulo - SP, 01307-002 600 m de distância - 8 minutos andando

### Hotel Riema Saint Charbel

R. Barata Ribeiro, 205 - Bela Vista, São Paulo - SP, 01308-000 90 m de distância - 1 minuto andando



APRIL 26-27, 2018 - SÃO PAULO - HOSPITAL SÍRIO LIBANÊS

### **Program**

### MAIN AUDITORIUM

First Day - Thursday, April 26, 2018

07:00 - 08:00 AM Late registration check-in

08:00 - 08:10 AM Welcome

Prof. Dr. José Otávio Auler Jr. (Director, FMUSP, São Paulo, Brazil)

Dr. Luiz Fernando Lima Reis (Director, Instituto de Ensino e Pesquisa do Hospital Sírio Libanês, São

Paulo, Brazil)

08:10 - 09:00 AM Opening Lecture

Everything you wanted to know about Big Data & Artificial Intelligence but were afraid to

ask

Speaker: Fabio Gandour (São Paulo, Brazil)

Moderator: Roberto Costa (FMUSP, São Paulo, Brazil)

09:00 - 10:00 AM Plenary Session: Vanderbilt University (Part I)

Moderator: Katia Regina da Silva (FMUSP, São Paulo, Brazil)

09:00 - 09:30 AM REDCap: How we started and where we are today

Speaker: Paul Harris (Vanderbilt University, USA) (video conference)

09:30 - 10:00 AM REDCap: What's New and What's Next?

Speaker: Rob Taylor (Vanderbilt University, USA)

10:00 - 10:20 AM Coffee-break

10:20 - 10:50 AM Plenary Session: Vanderbilt University (Part II)

Moderator: Katia Regina da Silva (FMUSP, São Paulo, Brazil)

10:20 - 10:35 AM REDCap: A Consortium View

Speaker: Brenda Minor (Vanderbilt University, USA)

10:35 - 10:50 AM Implementation and Impact of REDCap in Global Health Studies

Speaker: Stephany Duda (Vanderbilt University, USA)



10:50 - 12:00 PM Panel Discussion How REDCap Changed Research Culture across Latin American Institutions Moderators: Eduardo Abrantes (Hospital Sírio Libanês, São Paulo, Brazil) Leandro Amparo (FIOCRUZ, Rio de Janeiro, Brazil) 10:50 - 11:05 AM How REDCap Changed Research Culture: Hospital de Cancer de Barretos Speaker: Ricardo dos Reis (Hospital de Câncer de Barretos, São Paulo, Brazil) 11:05 - 11:20 AM How REDCap Changed Research Culture: Faculdade de Medicina de Ribeirão Preto, USP Speaker: Ricardo Perussi e Silva (Faculdade de Medicina de Ribeirao Preto (USP), São Paulo, Brazil) How REDCap Changed Research Culture: Clinica Alemana de Santiago 11:20 - 11:35 AM Speaker: Cristobal Carvajal (Santiago, Chile) 11:35 - 11:50 PM How REDCap Changed Research Culture: Fundacion Huesped, Argentina Mariano de Stefano Parma (Buenos Aires, Argentina) 11:50 - 12:00 PM Discussion Colloquium 12:00 - 12:30 PM REDCap: Planning, Collecting and Managing Data for Research and Quality Improvement **Programs** Speaker: Ceci Chamorro (Duke University, USA) Moderator: Luciano Kalabric (FIOCRUZ, Bahia, Brazil) 12: 30 - 1:30 PM **Lunch & Poster Competition** Poster's Moderators: Marcia Nagumo (REDCap-Brasil, São Paulo, Brazil) Sabrina Bernardez (Hospital do Coração, São Paulo, Brazil) Karlyse Belli (Instituto de Cardiologia - Fundação Universitária de Cardiologia, Porto Alegre, Brazil) Leandro Amparo (FIOCRUZ, Rio de Janeiro, Brasil) 1:30 - 2:40 PM Brazilian Hospitals Panel Using REDCap for Health Outcomes Measurement: Driving Clinical Change & Quality Improvement Moderators: Antonio Antonietto (Hospital Sírio Libanês, São Paulo, Brazil) Roberto Costa (FMUSP, São Paulo, Brazil) 1:30 - 1:45 PM Associação Nacional de Hospitais Privados (ANAHP) Speaker: Carlos Eduardo Sverdloff (São Paulo, Brazil) 1:45 - 2:00 PM Hospital Sírio Libanês (HSL) Speaker: Luiz Cardoso (São Paulo, Brazil) Hospital do Coração (HCor) 2:00 - 2:15 PM Speaker: Sabrina Bernardez (São Paulo, Brazil) 2:15 - 2:30 PM Hospital Moinhos de Vento (HMV) Speaker: Renata Muliterno Adamy (Porto Alegre, Brazil) 2:30 - 2:40 PM Discussion



2:40 - 3:00 PM	Colloquium Creative uses of standard REDCap Features / Tips & Tricks Speakers: Amanda Miller (University of Colorado Denver, USA) Linda Carlin (University of Colorado Denver, USA) Moderator: Cauane Blumenberg (Universidade Federal de Pelotas, Rio Grande do Sul, Brazil)
3:00 - 3:20 PM	Coffee-break
3:20 – 4:10 PM	Panel Discussion: Supporting REDCap  Moderators: Alvaro Ciganda (IECS - Instituto de Efectividad Clínica Sanitaria, Buenos Aires, Argentina)  Ricardo dos Reis (Hospital de Câncer de Barretos, São Paulo, Brazil)
3:20 – 3:35 PM	Administrative Support & User Policies Speaker: Ceci Chamorro (Duke University, USA)
3:35 – 3:50 PM	Training Models  Speakers: Amanda Miller (University of Colorado Denver, USA)  Linda Carlin (University of Colorado Denver, USA)
3:50 – 4:05 PM	Infrastructure management: small installations and how to grow then Speaker: Joseph Thomas (MD Anderson Cancer Center, USA)
4:05 – 4:10 PM	Discussion
4:10 – 4:50 PM	REDCap Interesting Use Case Competition: Oral Abstract Presentations  Moderators: Ricardo dos Reis (Hospital de Câncer de Barretos, São Paulo, Brasil)  Mark Munsell (MD Anderson Cancer Center, USA)
4:10 – 4:20 PM	Using REDCap as a companion in Electronic Health Records: facilitating structured data entry and extending secondary data use capabilities in the Intensive Care Unit.  Speaker: Cristobal Carvajal (Santiago, Chile)
4:25 – 4:35 PM	MAGENTA: A National Genetic Testing Study Conducted Using REDCap Speaker: Santiago Ramirez-Vargas (MD Anderson Cancer Center, USA)
4:40 – 4:50 PM	Integrating REDCap to a gamified web-based platform used in a birth cohort follow-up: the coortesnaweb project  Speaker: Cauane Blumenberg(Universidade Federal de Pelotas, Rio Grande do Sul, Brazil)
5:00 PM	Opening Ceremony & Social Activities



### MAIN AUDITORIUM

Second Day (Morning) - Friday, April 27, 2018

### Workshop 1 - REDCap: New users training

8:30 - 8:40 AM Welcome

Workshop Leaders: Kátia Regina da Silva (FMUSP, São Paulo, Brazil) Roberto Costa (FMUSP, São Paulo, Brazil)

Marcia Nagumo (REDCap-Brasil, São Paulo, Brazil)

8:40 - 8:50 AM REDCap: Overview

Speaker: Linda Carlin (University of Colorado Denver, USA)

8:50 - 9:20 AM REDCap: creating new projects

Online Designer, REDCap Library, XLM and ZIP file

Speaker: Amanda Miller (University of Colorado Denver, USA)

9:20 – 9:40 AM Classic & Longitudinal Projects: main differences

Speaker: Mariano de Stefano Parma (Fundacion Huesped, Buenos Aires, Argentina)

9:40 – 10:00 AM Data Collection

Speaker: Karlyse Belli (Instituto de Cardiologia - Fundação Universitária de Cardiologia, Porto Alegre,

Brazil)

10:00 - 10:20 AM Coffee-break

10:20 - 11:00 AM REDCap: main features

Data export & reports, User-rights and audit tracks, Survey

Speaker: Mark Munsell (MD Anderson Cancer Center, USA)

11:00 - 11:20 AM REDCap Mobile App

Speaker: Thais Talarico (Hospital de Câncer de Barretos, São Paulo, Brazil)

11:20 - 11:45 AM REDCap: Best Practices in Data Management and Lessons Learned

Speaker: Stephany Duda (Vanderbilt University, USA)

11:45 - 12:00 PM Discussion & Closing remarks



### AUDITORIUM #4 (Second floor)

Second Day (Morning) - Friday, April 27, 2018

Workshop 2 – REDCap: New Administrator

8:30 - 8:40 AM Welcome

Workshop Leaders: Jacson Barros (HCFMUSP, São Paulo, Brazil)

Eduardo Abrantes (Hospital Sírio Libanês, São Paulo, Brazil)

Jéssica Crivelari (REDCap-Brazil, São Paulo, Brazil)

8:40 - 9:00 AM REDCap Consortium Resources

Speaker: Brenda Minor (Vanderbilt University, USA)

9:00 - 10:00 AM REDCap: Operational Aspects

Installation and Upgrades, Configuration and Security, Gatekeeping and Governance, REDCap

tools, Regulatory aspects

Speakers: Joseph Thomas (MD Anderson Cancer Center, USA)

Rob Taylor (Vanderbilt University, USA)

10:00 - 10:20 AM Coffee-break

10:20 – 11:00 AM How to manage a REDCap instance at your institution?

Personnel and technical requirements & Gaining institutional support

Speakers: Alvaro Ciganda (IECS - Instituto de Efectividad Clínica Sanitaria, Buenos Aires, Argentina)

Cristobal Carvajal (Clinica Alemana de Santiago, Chile)

11:00 - 11:30 AM User Support Overview

Speakers: Ceci Chamorro (Duke University, USA)

Joseph Thomas (MD Anderson Cancer Center, USA)

11:30 - 11:45 AM REDCap: Best Practices and Lessons Learned (server, backups and development

environment, etc)

Speaker: Rob Taylor (Vanderbilt University, USA)

11:45 - 12:00 PM Discussion & Closing remarks



MAIN AUDITORIUM

### 12:30 - 1:30 PM Lu

Lunch & Poster Competition

Moderators:

Cleyton Oliveira (Hospital Beneficência Portuguesa, São Paulo, Brazil)

Cauane Blumenberg (Univesidade Federal de Pelotas, Rio Grande do Sul, Brazil)

Thais Talarico (Hospital de Câncer de Barretos, São Paulo, Brazil)

Marcia Nagumo (FMUSP, São Paulo, Brazil)

1:30 - 2:00 PM

Colloquium

Beyond Standard REDCap: API, Plugins, Hooks, External Modules, DDP and Other EHR

Interoperability

Speaker: Rob Taylor (Vanderbilt University, USA)

Moderator: Jacson Barros (HCFMUSP, São Paulo, Brazil)

2:00 - 3:00 PM

Panel Discussion

Integrating REDCap with Data Visualization Engines: R Program & QlikView

Moderators: Cauane Blumenberg (Univesidade Federal de Pelotas, Rio Grande do Sul, Brasil)

Joseph Thomas (MD Anderson Cancer Center, USA)

2:00 - 2:15 PM

REDCap & R Program

Speaker: Cristobal Carvajal (Clinica Alemana de Santiago, Chile)

2:15 - 2:30 PM

REDCap & R Program

Speaker: Jacson Barros (HCFMUSP, São Paulo, Brazil)

2:30 - 2:45 PM

REDCap & QlikView

Speaker: Eduardo Abrantes (Hospital Sírio Libanês, São Paulo, Brazil)

2:45 - 3:00 PM

Discussion

3:00 - 3:20 PM

Coffee-Break



3:20 – 4:00 PM	Innovation Spotlight Session: Healthcare Interoperability Moderator: Jacson Barros (HCFMUSP, São Paulo, Brazil)
3:20 – 3:35 PM	Healthcare Interoperability: Opportunities, Challenges and Solutions  Speaker: Tiago Calado (MV e HL7 Brasil)
3:35 – 3:50 PM	APIs and the Future of Healthcare Interoperability  Speaker: Allan Conti (Infor)
3:50 – 4:00 PM	Discussion
4:00 – 4:30 PM	Interesting Use Cases  Moderators: Ceci Chamorro (Duke University, USA)  Luciano Kalabric (FIOCRUZ, Bahia, Brazil)
4:00 – 4:10 PM	Combining REDCap with telemedicine to overcome geographical and financial barriers to aid in the treatment of skin cancer  Speaker: Anna Toner (Rice University, USA)
4:15 – 4:25 PM	Optimizing data management for Research involving Animals, from Research proposal to Vivarium and Animal Welfare registry based on REDCap.  Speaker: Cristobal Carvajal (Santiago, Chile)
4:30 - 4:50 PM	Future Perspectives REDCap across Brazil & Latin American Institutions: What's Next? Moderator: Roberto Costa (FMUSP, São Paulo, Brazil)
4:30 – 4:40 PM	REDCap across Brazil & Latin American Institutions: What's Next in Chile?  Speaker: Cristobal Carvajal (Clinica Alemana de Santiago, Chile)
4:40 – 4:50 PM	REDCap across Brazil & Latin American Institutions: What's Next in Argentina?  Speaker: Mariano de Stefano Parma (Fundacion Huesped, Buenos Aires, Argentina)
4:50 – 5:00 PM	REDCap across Brazil & Latin American Institutions: What's Next in Brazil?  Speaker: Kátia Regina da Silva (FMUSP, São Paulo, Brazil)
4:50 – 5:00 PM	Closing remarks and event dismissal
5:00 PM	Closing cocktail Announcement: Best Abstract & Best Poster (Voting process will finish by 3pm)



### **Oral Abstract session**

Thursday, April 26 - 4:10-4:50PM

Using REDCap as a companion in Electronic Health Records: facilitating structured data entry and extending secondary data use capabilities in the Intensive Care Unit.

Cristobal Carvajal and Cristopher Gumera, Clinica Alemana de Santiago

### Clinica Alemana de Santiago

From its first appearance in 1960s Electronic Health Records (EHR) have been a valuable source of medical data. Up to 70% of that relevant clinical information still exists as natural language in nonstructured text paragraphs (free-text). Although this model respects the usual clinical workflow and allows clinicians to read previous notes and provide clinical care, analyzing the textual portion of the record is very complex and defying task due to factors as ambiguity, uncertainty, complex temporal reasoning, complex terminology, heavy use of abbreviations, between others. Unlike free-text, structured information is computationally tractable and it is argued that it can be reused to support research, audit, and the clinical process. Normally extracting and aggregating natural language data from the EHR can only be accomplished by human coders, who identify and code relevant information onto separate databases for further analysis or clinical research. This process is distant from the data generation moment, time intensive, inefficient and error prone. Using REDCap, we developed a set of projects and forms to collect data in the 3 main medical instances: admission, transfer and discharge, for the Neonatal, Pediatric, Adult, Coronary and Neurologic Intensive Care Units (ICU). Each ICU had his own REDCap project and all forms were designed using as many structured variables as possible. We also included clinical scores (eg. PIM3, CHADS-VASC, STEMI, APACHE II, SOFA, etc). To motivate data entry, we give back to clinician a medical note in natural language based on the structured information they entered. For data visualization and analytics, we used Tableau that allows the ICU's to start doing data driven management. With more than 1200 hospitalizations until now, this use case shows that REDCap can be used in the clinical scenario offering structured data collection, semi-automatic natural language notes, clinical scores, analytics and decision support in the ICU.



### MAGENTA: A National Genetic Testing Study Conducted Using REDCap

Nadine Rayes, MD Anderson Cancer Center; Santiago Ramirez-Vargas, MD Anderson Cancer Center; Mark F. Munsell, MD Anderson Cancer Center; Karen H. Lu, MD Anderson Cancer Center

### **MD Anderson Cancer Center**

Background/Introduction: The MAGENTA (Making Genetic Testing Accessible) study aims to increase access to genetic testing by providing remote genetic services, which have traditionally been provided in-person or by telephone. We will recruit 3,000 women from across the United States who may be at increased risk to develop ovarian cancer. Participants undergo all study procedures remotely. Purpose: The REDCap project supports the conduct of a study to evaluate the effects of online genetic education alone vs. online genetic education with telephone genetic counseling on cancer risk distress. Methods The participant workflow begins with a public REDCap survey associated with our study website that assesses a potential participant's eligibility. Eligible participants are asked to electronically sign an online consent form that is delivered via the Automated Survey Invitation (ASI) tools. Following enrollment, participants receive baseline quality-of-life questionnaires (and at 3 other time points); the auto-notify feature monitors their responses and alerts study personnel during episodes of perceived distress. An API reads a report to automatically randomize participants who have completed these questionnaires to 1 of 4 study arms. Further, a new survey invitation provides them with a link to the genetic testing company's website, with an interface that is customized to the study arm conditions. Finally, a web service exports participant demographic, family history, and genetic testing data collected at the company into REDCap. Results Since April 2017, close to 3,500 women from throughout the U.S. have shown interest in the study, over 2,500 have completed the eligibility questionnaire, and almost 900 have enrolled. Half of these have received their genetic test results and learned about their cancer risk. Conclusion(s) REDCap's flexibility and user friendliness allowed us to create a highly convenient and consistent participant experience. Its powerful features have allowed our large nation-wide study to remain highly efficient, organized, and cost-effective.



Integrating REDCap to a gamified web-based platform used in a birth cohort follow-up: the coortes na web Project

Cauane Blumenberg, Federal University of Pelotas; Aluísio JD Barros, Federal University of Pelotas

### **Federal University of Pelotas**

Background: The Pelotas' birth cohorts comprehend almost 20,000 individuals who were born in the Southern Brazilian city. On average, every 2.5 years the members of the cohorts are followedup via face-to-face interviews, involving complicated logistics. In order to reduce logistic issues and shorten the gap between the follow-ups, other data collection methods should be exploited. Objective: Describe the development of the gamified web-based platform coortesnaweb, and its integration with REDCap to collect data and provide instant health-related results for the members of a birth cohort. Methods: The coortesnaweb was developed as a gamified platform to be used among the 1993 Pelotas birth cohort members. The gamification feature involves points and achievements, which are awarded to the participants after they respond to web-based REDCap surveys. The length of the REDCap surveys determines the amount of points earned after responding. These points are used to unlock health-related personal results, which are automatically calculated by the REDCap surveys and transmitted back to the coortesnaweb platform to facilitate visualization. The layout of the REDCap surveys was optimized to be as similar as possible to the platform. All surveys were designed containing branching logic and validation features to guarantee the quality of the collected information. Results: After two months, 3.318 members of the 1993 Pelotas birth cohort were invited via e-mail, Facebook and Whatsapp to register into the platform, 880 (26.5%) registered. Out of the 880 individuals registered, 533 (response rate = 60.6%) responded to the three REDCap surveys available in the platform which is equivalent to 1.599 records. REDCap could not calculate the results for only 22 (1.4%) records, because invalid answers for at least one item of the survey were provided. Conclusion: Integrating REDCap to a gamified platform is feasible. After a two-month period high response rates and low error rates were achieved.



### **Oral Abstract session**

Thursday, April 26 - 4:00-4:25PM

Combining REDCap with telemedicine to overcome geographical and financial barriers to aid in the treatment of skin cancer

Anna Toner, Rice University; Josh Raju, Rice University; Dr. Eric Richardson, Rice University; Dr. Carlos Eduardo Goulart Silveira, Hospital de Cancer de Barretos

### **Rice University**

This presentation details how Rice University, Hospital de Cancer de Barretos, and MD Anderson Cancer Center came together and addressed the need of a solution for dermatology treatment in rural parts of Brazil. We combined unique REDCap tools with the REDCap mobile app, allowing nurses from Hospital de Cancer de Barretos to safely and easily collect patient data from any remote location in Brazil. Some REDCap tools discussed in this presentation include: automatic email triggering, latitude and longitude tracking, photo capture and storage, and branching logic tailored to the patient's dermatologic state. This REDCap solution combined with an attachable cell phone dermatology device will provide a low-cost, safe and effective method for traveling nurses to treat patients who are geographically and financially constrained.



Optimizing data management for Research involving Animals, from Research proposal to Vivarium and Animal Welfare registry based on REDCap.

Cristobal Carvajal, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Catalina Vallejos, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Dominique Lemaitre, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Jorge Ruiz, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Camila Guzmán Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Valentina Aguilera, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo, Diego Baño, Facultad de Ciencias Físicas y Matemáticas Universidad del Chile; and Sebastián D. Calligaris, Facultad de Medicina Clinica Alemana-Universidad del Desarrollo

### Clinica Alemana de Santiago

Research studies involving animal experimentation are legally regulated by the Institutional Animal Care and Use Committee (IACUC). To this end, the IACUC must integrate information provided by investigators and by the veterinarians from the animal facility to monitor and improve the research process. The use of a paper-based system to collect data of animal health and welfare is a common practice, which is inconvenient in different ways, for example making timely and collaborative decisions between veterinarians and investigators when animals health or welfare is at risk. We developed a REDCap based system which enables data integration to offer a solution for data collection and reporting standardized animal welfare information. We used 5 different REDCap projects that communicate by Dynamic Queries (SQL), the projects are: Research Applications, Animal Welfare, Breeders, Matting, Litter & Allocation. Unlike other commercial software's available, this integral solution is focused on capturing the information from the whole research process which begins in the Research Application. Data collection considers also the registry of environmental conditions, animal housing and animal health data to facilitate the monitoring of animal welfare during preclinical research projects and animal breeding. The aim of the solution was to improve data collection inside animal rooms (tablet allowed it), and to optimize communication and sharing information between 3 main stakeholders: researchers, veterinarians and IACUC. This use case shows that REDCap can be used in the pre-clinical Animal Research scenario offering a data collection option for the whole preclinical Research process.



### Poster session:

Thursday, April 26

The impact of the use of REDCap in the routine of a Department of Epidemiology and Biostatistics: an experience of the use of Randomization.

Marco Antonio de Oliveira, Center of Epidemiology and Biostatistics - Barretos Cancer Hospital; Livia Hostalacio Mega, Center of Epidemiology and Biostatistics - Barretos Cancer Hospital; Isabela Queiros Castro, Center of Epidemiology and Biostatistics - Barretos Cancer Hospital; Marcos Alves de Lima, Center of Epidemiology and Biostatistics - Barretos Cancer Hospital; Thais Talarico Hosokawa, Center for Research in Molecular Oncology - Barretos Cancer Hospital; Larissa Cristina Ferreira, Center of Research Support - Barretos Cancer Hospital; Ricardo dos Reis, Center of Ginecology - Barretos Cancer Hospital.

### Fundação PIO XII - Hospital de Câncer de Barretos

Introduction: Barretos Cancer Hospital is one of the main referral centers for cancer treatment in Brazil. In the scope of the Research Institute, there is a Department of Epidemiology and Biostatistics, with 3 Statisticians. This Department supports researchers, and one of the offered services is the Randomization for Clinical Trials. Before joining the REDCap, this process was done manually, using Microsof Excel and deidentified envelopes. Objective: To share the experience of using REDCap in the support of randomization and to show the process of randomization through a real case. Method: We usually have a meeting with the researcher when we choose the stratifying variables, the blocks, and generate the vectors with the random sequence using the software R. The randomness between the blocks and within the blocks is kept using the sample function and the file is uploaded to REDCap. As a real case, the allocation group and the stratification variables were composed of 2 categories, the random sequence was created as follows: blocks of sizes 2, 4 and 6. Using functions block and sample, we generated the random sequences between blocks and within the blocks, obtaining the final random sequence. This process was replicated until we obtained the sequences for the group and for the stratifying variables. Results: Considering the projects in production mode 11 (6.25%) use randomization with our support. The time to randomize a patient is much lower than before: it's only necessary to fill the stratifying variables. Conclusion: The use of REDCap to conduct randomizations in research projects turned into a more reliable and fast process, allowing the researcher to have more autonomy in the study conduction. With this functionality, the Department of Epidemiology and Biostatistics optimized its time and is no longer necessary to have an employee available to perform the randomization.



The use of REDCap software platform (Research Eletronic Data Capture) in data storage in pulmonary thromboendarterectomy - ecocardiographic parameters

Orival de Freitas Filho, University of Sao Paulo; Edson Azevedo Simões, University of Sao Paulo; Laura Emilia Michelin Gobbo, University of Sao Paulo; Paula Gobi Scudeller, University of Sao Paulo; Fabio Antônio Gaiotto, University of Sao Paulo; Mario Terra Filho, University of Sao Paulo; Paulo Manuel Pêgo-Fernades, University of Sao Paulo; Fabio Biscegli Jatene, University of Sao Paulo

### Instituto do Coração-HCFMUSP

Introduction: Currently, the main treatment for chronic thromboembolic pulmonary hypertension (CTPH) is surgery by means of pulmonary thromboendarterectomy (PTE). This surgery requires clinical-surgical collaboration, and each team member is assigned to a role which is of fundamental importance in all phases of the treatment. Therefore, the creation of a unified database of patients submitted to PTE becomes important. In this context, echocardiography plays a prominent role, being an examination capable of evaluating important parameters of diagnosis, prognosis and severity. Objectives: To present the data storage platform in the PTE (REDCap) and results of the study evaluating the improvement of echocardiographic parameters in patients with CTPH undergoing PTE in InCor-USP. Methods: A retrospective study with 224 cases operated, of which 199 patients were added to the REDCap electronic database, 118 with echocardiographic evaluation in the pre- and postoperative period. In this study, the echocardiogram evaluated right ventricular contractility, presence of pericardial effusion, insufficiency tricuspid, left ventricular ejection fraction, presence of ventricular dilation, and reduction of systolic pulmonary artery pressure (SPAP). Results: A statistically significant difference (P < 0.05) was found when compared to preoperative and postoperative parameters, in the abnormal contractility of the right ventricle from 86.2% to 73.4%, reduction in cases of tricuspid insufficiency from 97.3% to 87.3%, reduction of cases with right ventricular dilatation from 92.2% to 64.7%, and reduction from SPAP 84.28 mmHg to 48.41 mmHg. Conclusions: PTE has been performed with similar results to the international reference centers. Echocardiography is considered an important tool for pre- and postoperative evaluation. The results of the data, using the electronic platform REDCap, in the PTE, will allow the accomplishment of several studies of high quality, safety, transparency, better integration among the multidisciplinary teams, ensuring the applicability of the protocols in a more efficient way and monitor their performance.



### Improving the data collection processes with REDCap using DDP (Dynamic Data Pull)

Guilherme Pacheco Aparicio, Barretos Cancer Hospital; Thais Talarico Hosokawa, Barretos Cancer Hospital; Dr. Ricardo dos Reis, Barretos Cancer Hospital; Dr. Renato de Castro Capuzzo, Barretos Cancer Hospital

### **Barretos Cancer Hospital**

Introduction: Barretos Cancer Hospital has been using REDCap in different departments, with a lot of data being collected daily. With this, it's important to have simple and objective data collection forms, so it can be as fast as possible. However, it's possible to verify that many patient data collected is already stored on the Institution Internal System (Sis-Onco) and without an integration, the data has to be filled manually on REDCap, a time-taking rework. The Dynamic Data Pull (DDP), a REDCap resource, allows thru a unique filled field, data search on the other system. Objective: Optimization of the use of REDCap, using the DDP functionality, in order to reduce the data collection time. Method: DDP is a REDCap standard module but the institutions willing to use it have to develop their own web services. All the necessary documentation can be found within REDCap installation webpage and also examples of projects of web services on GitHub - a developer's widely used repository. The web service was then created using the programming language PHP. Results: With DDP enabled and configured on a Project, every time REDCap searches for data thru the entered key, the web service receives a request via an URL and based on this request, searches the information on Sis-Onco system database (Oracle) and returns the data in JSON format. REDCap then interprets this output and populates the form automatically, for the mapped variables. Conclusion: With the DDP installation, was possible to identify a significant improvement in the process, reducing considerably the data collection time. This resource also helps on the dissemination of REDCap use on the institution.



### Validating clinical data using REDCap functions to the International Cancer Genome Consortium

Thais Talarico, Barretos Cancer Hospital; Letícia Ferro Leal, Barretos Cancer Hospital; Vinicius Vazquez, Barretos Cancer Hospital; Rui Manuel Reis, Barretos Cancer Hospital; Adriane Feijó Evangelista, Barretos Cancer Hospital

### **Barretos Cancer Hospital**

Introduction: Research in Cancer has taken the genomic direction, and Cancer Consortiums have revolutionized this scenario. One of the major is International Cancer Genome Consortium (ICGC) and Barretos Cancer Hospital is a member. These Consortiums have been generating high-quality publications, and the clinical data is fundamental to solve biological questions. Objective: Using REDCap resources to validate and improve the clinical data quality, allowing the Project members to communicate and solve issues before submission. Method: The data submission process opens from time to time by release and it includes a mandatory complex validation step (the whole process needs to be restarted until it validates). We chose a new type of tumor that was being included in the Consortium. The REDCap Project was developed using the ICGC vocabulary. Action tags were used, especially @PLACEHOLDER, to pre-populate the fields, when applicable. The design was set to consider the last follow-up. Data quality rules were built to check all the validation rules that are run by ICGC. Results: When the release was open for submission (it's done by ICGC granting us access to this section on data portal), researchers had checked the validation. They were responsible for data collection, running the rules and solving the issues found. Nine reports were created in the required format, including only the cases that were part of the release. The bioinformatician exported to R, grouping with the genomic files. Conclusion: The time-consuming process once experienced was skipped, on a safe metadata recording environment. The coordinator decided to replicate to other tumor types.



REDCap platform as an instrument of patient evaluation during an outbreak of yellow fever (YF) in an Infectious Diseases Intensive Care Unit (IDICU), São Paulo, Brazil, 2018

1Vieira L.T., 1Leite, G F C, 2Joelsons D, 3Ho Y-L, 2Higashino H.R., 2Nisida, I.V.V. 1Internal Physician, 2Assistant Professor, 3Chief Physician of Intensive Care Unit at Division of Infectious Diseases at Faculdade de Medicina da Universidade de Sao Paulo, Sao Paulo, Brazil.

### Division of Infectious Diseases at Faculdade de Medicina da Universidade de Sao Paulo

Background: Yellow fever is a mosquito-borne viral hemorrhagic fever with a high case-fatality rate. Severe disease is characterized by hepatic dysfunction, renal failure, coagulopathy, and shock. Purpose: In view of current outbreak in São Paulo, it was necessary to record the data and evolution of the IDICU patients, from January 9th to February 15th, 2018. METHODS A data sheet was prepared on the REDCap platform of confirmed YF cases, taking into account sociodemographic and epidemiological data, initial clinical presentation, organ systems affected and outcome (discharge from the IDICU or death). Results: 49 patients were considered: 41 (84%) male, with mean age of 43(SD= 15.5) years old; At admission it was registered the following complaints: fever 46(94%), myalgia 34(69%), headache 34(69%), nausea/vomiting 21(43%), clinical bleeding 16(33%) and jaundice 8(16%). The organ systems affected were: hematologic (coagulopathy) 39(80%), renal failure 39(80%), fulminant hepatitis 30(61%), hemodynamic shock 27(55%), acidosis 34(70%) and seizures 13(27%). Discharge and mortality from IDICU were respectively 20(31%) and 29 (59%). Conclusion(s): The REDCap platform proved to be very useful in evaluating patients in the outbreak of YF in critically ill patients, synthesizing the evolution data and suggesting formulations for research.



### How to Introduce REDCap Platform in your Institution?

Ricardo dos Reis (research assistant professor), Marco Antonio de Oliveira (statistician), Guilherme Aparecido Pacheco (informatic technician), Livia Hostalacio Mega (statistician), Marcos Alves de Lima (statistician), Isabela Queirós Castro (statistician), Thais Talarico Hosokawa (statistician).

### **Barretos Cancer Hospital - Loves Hospital**

Objective: Explain how to introduce REDCap platform in a new research and educational institution. Method: We are going to expose how to introduce the REDCap platform in a new institution, how much time and emphasize the most important steps to have success in this installation. Results: In 2014, one of the members of our REDCap team learned to work with REDCap at M D Anderson Cancer Center and he decided to install in our institution. The first step is to convince the directors of your institution about the importance of REDCap. In this step, the most important aspects to explain about this program are:1) The platform is totally trustworthy in terms of data storage; 2) The data included in this platform is storage in own server; 3) The patient data will keep storage in our institution and not in particular computers or devices. After to convince the directors, the second step is to create a REDCap team in your institution with: medical doctors, nurses, informatics technician, research coordinators and statisticians. The third step in REDCap introduction is to present the platform to your hospital, first to research community and after to the administrative community. It is very important to clarify that the data is not storage in the Vanderbilt University, they only created and keep the program. Another important aspect is to emphasize that you can include data in offline mode and you can access your data wherever you are. Conclusion: We took one year for all process of installation of REDCap in our institution and one year more to spread the program in all institution, for research and administrative projects. Today, all projects approved by our IRB has to be in REDCap platform. In conclusion, we think that is necessary two years for implementation of REDCap platform.



### The functionality of REDCap in the palliative care unit

Felipe Coutinho Zago, Hospital de Amor de Barretos

### **Hospital de Amor Barretos**

It is important to show how much the palliative care unit has evolved in a short period of time through the use of Redcap, as well as scientifically promote this evolution. The use of the Redcap in the Palliative Care Unit has been in progress since June 2017. This period is considered a milestone in the data analysis, in the visualization of management indicators and work done by all the staff. At first it was implanted for outpatient follow-up of patients who were palliated by the hospital clinical staff. We therefore sought to respond only to the specialties and conditions of referral. Regular, standardized and computerized procurement brings us a more practical solution to daily adversities- through the collection of data from month to month and the analysis of historical series it promotes recognizing problems and designing action plans, thus optimizing human and financial resources, effectively dimensioning teams to improve care. Redcap is an auxiliary tool in palliative hospital management. Today, the Unit applies it in 90% of its departments with data collected by the system, which clarifies the daily work, care and management with greater transparency. From this point on, it becomes more efficient the studies carried out in relation to literary references. Nowadays, with the use of the redcap, it is possible to map all the departments that the patients use in the unit, comprising outpatient care, hospitalization, intercurrences, home care, socio-demographic analysis (it is possible to trace the profile of the patient who reaches palliative care), medication dispensing, pain control, postdischarge follow-up, patient's referral to the service by the specialties, among other data. It is notorious that the use of Redcap along with data administration and hospital management form great allies in the constant search for excellence and humanized satisfaction for the patient's wellbeing.



### Use of data quality assurance tools within the REDCap

Livia Hostalacio Mega, Hospital de Cancer de Barretos, Marco Antonio de Oliveira, Hospital de Cancer de Barretos, Marcos Alves de Lima, Hospital de Cancer de Barretos, Isabela Queirós Castro, Hospital de Cancer de Barretos, Thais Talarico Hosokawa, Hospital de Cancer de Barretos, Guilherme Aparecido Pacheco, Hospital de Cancer de Barretos, Ricardo do Reis, Hospital de Cancer de Barretos

### Hospital de Cancer de Barretos

Introduction: The Epidemiology and Biostatistics Department is part of the Teaching and Researching Institute of the Barretos Cancer Hospital. The main goal of the Department is supporting researchers in any process related to data, assisting since the determination of the variables to be collected to the interpretation the statistical results. The department counts on a database manager dedicated to the construction of the databases and quality assurance of the data, what is accomplished almost entirely using REDCap. Objectives: The objective of this work is to present the workflow to perform data consistency and the techniques for ensuring the quality of the data in addition to the correction of possible errors that still may occur during the data collection. Methods: to perform the data consistency, are used several REDCap functions that could use the external tools if this is necessary. Of these, we highlighted some functions from applications: data quality module and additional customizations. Conclusions: It is possible to notice an increase in the time spent for the construction of the database since more useful configurations for the collection are necessary, as well as the determination of the format of the database. However this time is offset by the significant reduction of time spent in the new form of consistency, which fell from an average of 6 hours to 2. Currently, we develop projects using REDCap only but we still have some projects that started with paper-based data collection. Even if we need to rebuild these projects on REDCap and upload the database, we can have advantages because they show a better operability to deal with the data, making it possible to guarantee beyond the dynamics of excellence to collect, the data security and attendance of good practices in an optimized time.



# The RE-Heart Registry: A prospective, interoperable, standardized clinical registry of outpatients with heart failure

Cristiane Vacca, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC) and REC Saúde; Maria Antonieta Moraes, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Gabriel Garcia, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Marcelo Filippe, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Roberto Sant'Anna, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Marciane Rover, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Clarissa Rodrigues, Global Research and Innovation Network (GRINN)

### **Global Research and Innovation Network - GRINN**

Background: Heart failure (HF) is a global epidemic which affects about 5.1 million people only in the US and costs an estimated 32 billion dollars a year. Thus, there is an urgent need for better control of clinical outcomes and costs, based on highly accurate data. Purpose: To describe the creation of the RE-Heart Registry, a prospective, interoperable, highly scalable and standardized clinical registry of outpatients with HF. Methods and Results: We conducted the following steps: (1) Data standardization in accordance with national and international data elements. Dataset included all applicable standardized data elements published by the American Heart Association/American College of Cardiology, European Heart Failure Registry and Brazilian national heart failure and demographics datasets; (2) Development of an initial data collection and clinical research workflow; (3) Development of electronic case reports using REDCap and in accordance with the HIPAA privacy rule; (4) Pilot test and validation of the data collection and clinical research workflows and CRFs, (5) Development of automated data quality report using REDCap. Patients are included if they are 18 years old or more and are diagnosed with HF (Boston criteria) and are excluded if they do not agree to participate. Data collection occurs at the outpatient department at the moment of inclusion and every 6 months (phone calls and visits to the outpatient's department). Clinical and cost-related outcomes include all-causes mortality, cardiovascular mortality, non-fatal myocardial infarction, stroke, hospital admissions, visits to the emergency department, costs related to the treatment and procedures, and quality of life. Conclusions: The RE-Heart Registry represents a comprehensive database capable to represent real clinical practice favoring clinical research, technology assessment, services management and health policies. By using standardized and interoperable methodologies, the RE-Heart Registry allows for data integration among datasets, enhancing datasets and leveraging information to help HF patients.



# Experience of the Digestive System Organ Transplantation Service - HC FMUSP with software based on research and electronic data capture - RED Cap

Jairo Moreira, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Luciana Haddad, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Rodrigo Bronze, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Vinicius Santos, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Liliana Ducatti, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Rubens Nascimento, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Rubens Nascimento, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Rafael Pinheiro, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; Wellington Andraus; Luiz Carneiro, Division of Digestive Organ Transplantation, School of Medicine, University of São Paulo; University of São Paulo

### Hospital das Clínicas da Faculdade de Medicina de São Paulo

Experience of the Digestive System Organ Transplantation Service - HC FMUSP with software based on research and electronic data capture - RED Cap Introduction: With the technological advances, the Liver Transplant Service of HC FMUSP realized the need to obtain a tool that could store and manage its information. Initially, the Microsoft Access Database was used. Objective of this study was to evaluate the effectiveness and performance of the RED Cap database in the HCFMUSP Liver Transplantation Service. Method: A project was created in the RED Cap 'Prospective Evaluation of Liver Transplantation' by the research coordinators, this project was previously approved by the Research Ethics Committee (CEP) and Plataforma Brasil. All subjects submitted to liver transplantation were included in the current 2002 period. The Access database was used as the reference base for creating the data dictionary, due to its contribution of information. Reports and protocols were also used in the service. All forms were previously reviewed by members of the research team prior to the start of the study and a performance evaluation was applied. Results: Acquired with the effectiveness of RED Cap: 23 surveys, 06 forms, 818 fields and 1276 records of patients submitted to liver transplantation, each record with photos of the organ captured, explant and revascularization. The data are 100% up-to-date, 149 customized reports have been created to answer survey questions, which can be refined and visualized in the basic statistics of the software throughout the longitudinal study period, as quality rule is periodically carried out audits of the computed information set and data backups. Conclusions: RED Cap offers opportunities for project-specific online queries, data storage, and validation procedures and data security, offers a form layout and is an effective repository for research.



### Use of redcap in a multidisciplinary hypertension ambulatory

Luíza Junqueira Trarbach, Instituto de Cardiologia; Michelle Santarém, Hospital de Clinicas de Porto Alegre; Liliana Fortini Cavalheiro Boll, Instituto de Cardiologia; Bruna Eibel, Instituto de Cardiologia; Karlyse Claudino Belli, Instituto de Cardiologia; Maria Claudia Irigoyen, Instituto de Cardiologia e Silvia Goldmeier, Instituto de Cardiologia

### Instituto de Cardiologia

Background/Introduction: Research electronic data capture (REDCap) is a workflow methodology and software designed for development and deployment of electronic data capture tools. Meticulous collection of clinical outcomes data in medical clinic hypertensive patients are important to ensure quality care. Purpose: This study assesses an electronic and systematic method for the monitoring of patients to optimize the results by standardizing the inclusion of data. Methods: The electronic data collection started at March 2015 when the patients were actively enrolled for a year, during which data was continuously being completed by the whole team. The team was composed by nurses, nutritionists, psychologists and physiotherapists. They are trained to fill the standardized questionnaire data on the platform at each consultation for one year, every 2 months. This possibility can promote an equal and qualified knowledge by all professionals of the medical clinic, being used as a tool for the outcomes of a randomized clinical trial. Considering the consistency and ease of medical reporting, as well as the prescription, this method generates a standardized text which is copied for institution's electronic health record system. Results: During the 2 years in which this process has been used the outcome data have been collected (109 patients) at one time point to create an institutional database. This system allows the tracking of patients' outcomes data and the use of the institutional database for future research in an easy, secure and flexible way. Conclusions: A REDCap platform could be easily used for gathering medical clinic data and to generate an automatic medical report in hypertensive patients. It causes less mistakes such as double collection from the same patient and data transcription errors and is possible to have the descriptive results from ambulatory in the same moment of completion of any patient.



## Using REDCap for data management in the Prospective, Multicentre Clinical Registry of Hypertension in Children and Adolescent - HASCA Registry

Clarissa G. Rodrigues, Global Research and Innovation Network (GRINN); Jacqueline Vaz, Instituto de Cardiologia da Fundação Universitária de Cardiologia (IC/FUC); Ana Gabriela Haussen, Instituto de Cardiologia da Fundação Universitária de Cardiologia (IC/FUC); Caroline Naidon Coelho, Instituto de Cardiologia da Fundação Universitária de Cardiologia (IC/FUC); Liliana Fortini Cavalheiro Boll, Instituto de Cardiologia da Fundação Universitária de Cardiologia (IC/FUC); Lucia Pellanda, Instituto de Cardiologia da Fundação Universitária de Cardiologia (IC/FUC); Maria do Carmo Pinho Franco, Universidade Federal de São Paulo (UNIFESP); José Geraldo Mill, Universidade Federal do Espírito Santo - Departamento de Ciências Fisiológicas (UFES/DCF); Lucélia Magalhães, Universidade Federal da Bahia (UFBA); Cristiano Mostarda, Universidade Federal da Bahia (UFBA); Maria Silvia F. R. C. Moraes, Faculdades Integradas Aparício Carvalho (FIMCA); Milcíades Alves de Almeida, Instituto Luterano de Ensino Superior de Porto Velho (ULBRA ILES); Marcelo Rubira, Instituto Luterano de Ensino Superior de Porto Velho (ULBRA ILES); Fernanda M. Consolim-Colombo, Instituto do Coração do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo (INCOR/HCFMUSP) and Universidade Nove de Julho (UNINOVE); Maria Cláudia Irigoyen, Instituto do Coração do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo (INCOR/HCFMUSP)

### Global Research and Innovation Network (GRINN)

Introduction: Hypertension is now commonly observed even in the paediatric population. The disease is one of the main risk factors for cardiovascular disease and is associated with poor prognosis and elevated medical costs. Despite its importance, high quality data about diagnosis and treatment of hypertension in children and adolescents are still not available. Objective: To describe the implementation of a prospective, multicenter clinical registry to document the clinical practice of diagnosis and treatment of hypertension in children and adolescents, in Brazil. Methods and results: 8 Brazilian centers are included in the study. Eligibility criteria: age from 7 to 18 years, both sexes, with primary hypertension in any stage and/or overweight/obesity. Study is divided into: Phase 1 - Screening in schools with verification of weight, height, waist circumference and blood pressure. Phase 2 - Individuals meeting inclusion criteria will participate in phase 2. Assessed variables: socio-demographic, child and family medical history, clinical investigation and classification of hypertension, weight, height, BMI, waist circumference, exercise and eating habits, prescribed pharmacological and non-pharmacological therapy, target organs complications, frequency of medical appointments, and complementary exams. Data will be collected every 3 months since the inclusion. Electronic case report forms (CRFs) were built in REDCap, using standardized data elements in accordance with national and international references, and in



accordance with the HIPAA privacy rule. Pilot tests of CRF and clinical research workflow were conducted before the national data collection starts, and automated data quality report using REDCap are used. Data are stored on a local server with individual and non-transferable password access. Included centers receive on-line training and a manual available for consultation. Conclusions: The use of REDCap allowed us to build a high quality, standardized and interoperable registry to document clinical practice related to diagnosis and treatment of hypertension in children and adolescents in Brazil.

# APRIL 26-27, 2018 - SÃO PAULO - HOSPITAL SÍRIO LIBANÉS REDCAPCON R

### Management model of REDCap at Sírio-Libanês Hospital: virtues and weaknesses

Eduardo Fernandes Abrantes, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Felipe Elias dos Santos Cardoso, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Leandro de Moraes, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Debora Santos de Oliveira, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês and Luiz Fernando Lima Reis, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês.

### Sociedade Beneficente de Senhoras Hospital Sírio-Libanês

The Institute of Education and Research (IEP) of Sírio-Libanês Hospital (HSL) adopted REDCap at the end of 2011 as a tool for electronic data capture with the objective of supporting specific research projects that demanded more rigor in the data collection process and management. The use of REDCap ended up being disseminated in the Institution and this platform began to be used in several projects that demanded data collection, with emphasis on the hospital care areas that aim to obtain data and operational indicators of the Institution. With increasing demand for project development and platform use, the IEP has defined a policy for REDCap use in HSL. In this context it was defined that the administration and development of projects would be centralized in a single team defined as the Research Support Information Systems (SIAP). The justification when adopting such a model was based on the perception that the centralization of the development could give greater quality and consistency to the developed projects, allowing the Researcher or collaborators of the HSL to invest more effort in the definition of variables and planning of the operation of the project. It was up to the SIAP team to develop and/or adopt tools to manage the queue of REDCap project development requisitions or activities related to project data management in production. Therefore, all requests for the development of REDCap projects must be registered in a system called AVAP-NG (Virtual Environment for Research Support) in which the project will undergo an initial technical evaluation and subsequently prioritized by the IEP Board based of the priorities of the Institution. Several institutions in Brazil have adopted the REDCap and different management models of this tool. For each model it is possible to define merits and fragilities and each model must be considered according to the reality



#### Synergy between REDCap and Biobanks: the model used at Sírio-Libanês Hospital

Eduardo Fernandes Abrantes, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Alice Chaves dos Reis, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Tatiana Marques Ferreira da Rocha, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Luiz Fernando Lima Reis, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês.

#### Sociedade Beneficente de Senhoras Hospital Sírio-Libanês

The Biobank of the Sírio-Libanês Hospital (HSL-Biobank) was created in 2012 as a strategic initiative to leverage new research opportunities in this institution. Reflecting the institution's multi-specialty character, HSL-Biobank implemented different scenarios for the collection of biosamples, including Surgery Center, Critical Care Units and Oncology Center. All of the collection processes management is carried out by the SIB-Sírio system (Biobank Information System of the Sírio-Libanês Hospital), a Web-based platform developed by the Research Support Information Systems (SIAP) team of the Institute of Education and Research (IEP) of Sírio-Libanês Hospital. Although the SIB-Sírio has been efficient in managing the processes of the HSL-Biobank, this tool was not developed to collect clinical information. Obtaining reliable clinical information related to the stored samples has been a great challenge for the vast majority of biobanks in Brazil and worldwide. REDCap has been used to create specific databases for the HSL-Biobank, for example, parameterized forms to collect data from anatomopathological reports. But REDCap has also been used to develop project-specific database for subsets of specific samples. In another approach, we are trying to map others REDCap projects that could have relevant clinical information related to samples stored at HSL-Biobank. This process has been carried out with the support of Business Intelligence tools that integrate the SIB-Sírio platform with a specific set of REDCap projects. This approach has been possible since the SIAP team centralizes the development of all REDCap projects at Sírio-Libanês Hospital as well as the development of SIB-Sírio software. The purpose of this work is to describe the use of REDCap to support clinical information capture and recycling for the HSL-Biobank.



# Using REDCap for managing administrative aspects of and quality indicators of research projects

Clarissa G. Rodrigues, Global Research and Innovation Network (GRINN)

#### Global Research and Innovation Network (GRINN)

Introduction: One of the main difficulties of institutions and research centers working on several research projects concomitantly is to manage the administrative aspects ensuring timely deadlines, complete reports and compliance with regulatory agencies. Objective: To describe the creation of a database in the Research Electronic Data Capture (REDCap) system to manage administrative aspects of research projects. Methods and results: We used the resources available in REDCap to build a database with more the 4 thousand fields to manage research projects. Main characteristics: (1) Entrance of new projects: options are available through survey and/or login and password, as appropriate. System generate email alerts to the research team every new project registered in the dataset, so actions can be taken; (2) Co-authors awareness: each listed co-author receives an automated email informing his/her inclusion in the project and asking to confirm their participation. Responses are automatically integrated into the dataset; (3) Automated reports: different reports, e.g. for institutions, investigators and regulatory agencies purposes are built automatically in real time; (4) Researcher access to their own projects. The multicenter features of REDCap are used to give researchers access to their own projects where they can visualize data and export selected reports; (5) Linked instruments and branching logic are extensively used to automate and personalize data for the needs of each study; (6) Scientific production: abstracts, scientific papers and book chapters linked to the projects can be store at the same dataset and are part of the automated reports, as necessary; (7) Sponsorship and deadlines: information on sponsorship and deadlines are included into the datasets and automated alerts are generated as appropriate for each study. Conclusions: The use of REDCap allowed us to adequately manage the administrative aspects and quality indicators of research projects saving time and costs when conducting clinical studies.



#### REDCap as tool for organizing oral cancer screening

Vazquez, F.L.; Talarico, T.; Reis, R.M.; Gama, R.

#### **Hospital de Cancer de Barretos**

Introduction: Oral cancer screening requires the use of a systematized information database that the patients was be traceable and reliable. In addition, well-defined diagnostic and prognostic information contained in the same database are fundamental. Objective: Using REDCap resources to facilite and improve the clinical data quality, molecular and diagnosis tests, making possible to organize oral cancer screening. Method: Barretos Cancer Hospital has an Oral Cancer Prevention Department that offers cancer prevention consultations for at-risk patients (smokers and alcoholics over 40) since 2014. The Department have a mobile unit that travels through the areas, attending this population with for an oral cancer high risk. The REDCap project was developed so that all patients seen were enrolled and turned to routine exams, thus organizing oral cancer screening. Results: The clinical, epidemiological and molecular data of each participant were stored in the same database, which facilitated and enabled individualized follow-up and patient return for routine exams, prevention and treatment when necessary. Conclusion: A unique database with diverse information enabled the organization of oral cancer screening for the first time in Brazil.



Challenges on implementing REDCap as a research management tool in a Brazilian public university setting

Fernando A.B. Colugnati, Medicine School/ UFJF

#### Faculdade de Medicina/ Universidade Federal de Juiz de Fora

Federal University of Juiz de Fora (UFJF) is part of REDCap consortium since 2013. More than 30 projects were managed using the platform, comprising more than 3.000 research subjects. Clinical trials, multicentre clinical research, epidemiologic studies, e-mail surveys and even the development of an electronic register for a smoking treatment unity were feasible mainly because of this tool. However, many barriers have postponed the complete implementation of REDCap in the institution, regarding problems on infrastructure, human resources and the university governance. This talk aims to discuss with the audience these barriers promoting the exchange of experiences on similar institutions, providing solutions for some problems like platform governance and project policy, sustainability, management and support for users.



#### Poster session:

Friday, April 27

#### Latin American Neurotrauma Registry: LATINO Project

Yesid Araque, Universidad El Bosque; Pierre Y. Fonseca, Universidad El Bosque; Sandra L. Olaya, MEDITECH Foundation; Ricardo Borda, Universidad El Bosque; Gerardo Aristizábal, Neurosciences Institute, Universidad El Bosque; Juan C. Puyana, University of Pittsburgh; Andrés M. Rubiano, Neurosciences Institute, Universidad El Bosque

#### Universidad del Bosque

Introduction For many years Latin America has contributed poorly with the global epidemiological reports in neurotrauma. Neurotrauma is a public health problem in the Latin American region due to the social and economic impact. Due to this, it is necessary to create an electronic regional registry to collect clinical data for understand care ecology and clinical outcomes of neurotrauma patients of the region. Objective Build the first on-line registry for neurotrauma patients, available 24 hours a day with remote access from anywhere in the region. The frame for this project will be a partnership for a collaborating center of the World Health Organization based in Bogotá/Colombia. Materials and Methods The registry was build through REDCAP, allowing encrypted remote access for regional reference centers that are part of the Latino research network. Results 244 variables were included, divided into demographic, prehospital, emergency, surgery and intensive care topics, harmonized with the Common Data Elements project of the U.S. National Institutes of Health. Discussion Specialized trauma registries are fundamental in order to develop capacity for trauma care organization in low and middle-income economies. Similar regional efforts have created important advances in disease understanding for decision-making process at political level. Conclusion. The development of a neurotrauma registry for Latin America is possible and it will allow generating an important number of data for multicentric analysis of the quality of care associated with clinical outcomes. Key words: neurotrauma, trauma registry, quality control, patient safety



#### Redcap validation at the National Institute of Cardiology (INC)

Rose Mary Frajtag, Instituto Nacional de Cardiologia; Luciana Rodrigues de Almeida Figueiredo, Instituto Nacional de Cardiologia; Helena Cramer Veiga Rey, Instituto Nacional de Cardiologia; Tereza Cristina Felippe Guimarães, Instituto Nacional de Cardiologia

#### Instituto Nacional de Cardiologia

Introduction: The National Institute of Cardiology develops researches in the area of cardiovascular sciences, being essential to use a safe and effective tool to optimize the storage and management of data in all phases of the research. Purpose: Validate the Redcap platform at the National Institute of Cardiology as an institutional instrument that aims to standardize research data at the INC. Methods: In order to validate the use of the Redcap platform at the National Institute of Cardiology, it was initially used as part of the clinical study titled 'Telecardiology in Support of Clinical Decision in SUS'. To do this, a record (CRF) was created as a tool for the collection of clinical and operational data of patients who participated in the clinical study and performed an electrocardiogram at Family Clinics in the city of Rio de Janeiro. Based on the CRF, the database was developed through Redcap, where all patients' information was stored, as well as information about their follow-up for 12 months, using platform resources such as calendar and event management. Results: The use of Redcap enabled the collection of clinical and operational data with quality, monitoring, management and traceability of the information collected, as well as the generation of reports and the optimization of the analysis of the results. Conclusion: Redcap will be used as an institutional tool aiming the standardization of research data at INC.



REDCap platform as a multidisciplinary healthcare team (MHT) research tool on sexual violence (SV): features of children victims younger than 10 in Sao Paulo, Brazil, 2001-2013.

Nisida, I.V.V.1; Boulos, M.I.C1; Alberguini S.2; Silva L.M.B.3; Nascimento M.4; Segurado A.C. 5 Infectious Disease Physician, 2Social Worker, 3Psychotherapist, and 4Nurse, Rape Care Center (RCC), Infectious Disease Division, Hospital das Clinicas, Faculdade de Medicina da Universidade de Sao Paulo (HCFMUSP); 5Director, Division of Infectious Diseases, at HCFMUSP.

Rape Care Center , Infectious Disease Division, Hospital das Clinicas, Faculdade de Medicina da Universidade de Sao Paulo , Brasil

Background: Diagnosis of sexual violence (SV) during childhood is a difficult task. Purpose: To describe characteristics of children younger than 10, who were brought to the RCC, in Sao Paulo as victims of SV, using REDCap as an electronic data capture tool. Methods: A REDCap platform was elaborated in 2014 to register data of a retrospective medical chart review of patients who were brought to the RCC as victims of sexual violence from 2001 to 2013. Variables of interest included sociodemographic data, SV characteristics, physical examination findings and retention in follow-up for 6 months after the SV episode. Results: Out of 95 children, 54(57%) were female, 67(70%) white, mean age 5 (SD=2.6) years old.; 59(63%) children were brought to the RCC 72 hours after the SV episode. 35(40%) children reported being chronically abused and 49(52%) informed the violence episode occurred at home or nearby. 27(28%) perpetrators were not identified. 38(64%) of declared perpetrators were known by the victims. As for the SV characteristics, 56(82%) episodes involved one perpetrator only, and were described by girls as 21(37%) vaginal penetration (10 by penis or 11 by any object). When victims of both sexes are considered, 20(21%) victims reported anal penetration (15 by penis or 5 by any object) and 40(43%) were sexually touched; on clinical examination 50(50%) had positive physical or genital findings. 17(18%) children presented genital papillomavirus and 9(53%) of those were presumed to have been acquired it by household contact at final MHT evaluation. 42(44%) victims completed the proposed 6-month follow-up, 17(38%) of those patients SV wasn't consensus at final MHT evaluation. Conclusion: The diagnosis of SV in children aged under10 is a challenge in face of poor physical evidence. REDCap proved to be a useful tool for deployment in clinical research in these circumstances.



REDCap Platform as a teaching tool for students attending a scientific initiation program with a study on the prevalence of sexual dysfunction in subjects seeking treatment for HIV/AIDS in São Paulo,

1Salvestrini L.: 2Nisida IVV, 3Amaral MLS, 3Reis SC Messina B., 3Segurado AC, 4Scanavino MT. 1Faculdade de Medicina, Universidade de Sao Paulo (FMUSP), São Paulo, SP, Brasil. 2Divisão e 3Departamento de Moléstias Infecciosas e Parasitárias, 4Departamento e Instituto de Psiquiatria (IPq), Hospital das Clínicas HC-FMUSP.

Divisão e Departamento de Moléstias Infecciosas e Parasitárias, Departamento e Instituto de Psiquiatria, Hospital das Clínicas da Faculdade de Medicina de Sao Paulo. Brasil

Introduction: Research electronic data capture (REDCap) is a workflow methodology and software for development and deployment of electronic data capture to support clinical research. Purpose: To evaluate the REDCap Platform as a teaching tool for students who participated in a scientific initiation program. Methods: The 'Prevalence of sexual dysfunction and associated factors in subjects seeking treatment for HIV/AIDS' was a study approved in 2013. Students involved in research at the Departments of Psychiatry and Infectious Diseases inserted the measures and applied them through the REDCap. Computerized questionnaires (CQ) were used to assess sociodemographic data, information on clinical management of HIV infection, sexual risky behavior, and validated tools, such as ABCD (Adult AIDS Clinical Trials group assessment of body image and distress), Beck depression/anxiety inventories; MINI-International Neuropsychiatric Interview (alcohol and drug use); and sexual dysfunction for males (International Index of Erectile Function) and females (Female Sexual Function Index) scales. Students were instructed to apply CQ to patients who were randomly selected. The first CQ were applied by students and the others were self-responsive (reducing information bias) also through REDCap. Besides their involvement in data collection students were encouraged to select specific variables from the dataset for statistical analysis and present preliminary results to the lab team, and in scientific events, as part of scientific initiation activities. Results: 11 students participated in this study as: one student on inclusion of our measures in the REDCap platform; 11 on applications of CQ to 296 males (170 included) and 193 females (63 included) outpatients; 11 presented orally results to Psychiatry team; 8 students presented poster at national/international events in Brazil. Conclusion: From the point of view of academic results, the REDCap has proven very useful to the acquisition of research skills and contributed favorably to the scientific output of students.



#### Automated Post-Travel Surveys in REDCap in a Travel Medicine Clinic

Margareth Catoia Varela, Clinical Research Laboratory on Health Surveillance and Immunization - National Institute of Infectious Diseases Evandro Chagas (FIOCRUZ); Elizabeth de Souza Neves, National Institute of Infectious Diseases Evandro Chagas (FIOCRUZ); Teresa Beatriz Pereira, Clinical Research Laboratory on Health Surveillance and Immunization - National Institute of Infectious Diseases Evandro Chagas (FIOCRUZ); Marcellus Dias da Costa, Clinical Research Laboratory on Health Surveillance and Immunization - National Institute of Infectious Diseases Evandro Chagas (FIOCRUZ)

# Clinical Research Laboratory on Health Surveillance and Immunization - National Institute of Infectious Diseases Evandro Chagas (FIOCRUZ)

BACKGROUND: Travel medicine is a specialty that focuses on pre-travel preventive care and on surveillance and treatment of diseases in returning travelers. Usually, people seek a travel medicine clinic for pre-travel advice and consultation, and post-travel information is difficult to be systematically monitored. A study using REDCap was planned to obtain post-travel data to evaluate adherence and effectiveness of pre-travel recommendations. OBJECTIVES: Use REDCap to provide a structured, fast, low-cost and systematic method for gathering relevant post-travel information about the health of returning travelers. METHODS: A form was created where identification information is registered when the traveler has a consultation at the travel medicine clinic. This information includes email address and return date of the trip. A survey containing 14 post-travel questions, with a total of 34 fields, some hidden by branching logic, was set with automated invitations, where a conditional was specified to schedule the invitation to be sent after 7 days from the return date. A reminder was enabled to be sent after 7 days of no response. To support tracking of nonrespondents, a custom report was created containing data from travelers that did not respond the survey after the reminder was sent. RESULTS: Since October 2017 the travel medicine clinic of the National Institute of Infectious Diseases Evandro Chagas (INI/FIOCRUZ) has an electronic post-travel database, and patients continue to be actively enrolled. The steps for creation and set up of the project in REDCap were done in a few days after the conception of the study, allowing the project manager to concentrate on active search and data analysis. CONCLUSIONS: REDCap allowed all steps that involve managing the schedule of the return dates of travelers to be automated, not only dispensing labor but ensuring quality and efficiency improvement of these tasks.



# Evaluation of anthropometric measures and correlation with cardiovascular outcomes of patients with chronic heart failure

Leticia Soares Marinho, University of Sao Paulo Fabiana G Marcondes-Braga, Heart Institute - University of Sao Paulo Sabrina Bernardez-Pereira, Heart Institute - University of Sao Paulo Fernando Bacal, Heart Institute - University of Sao Paulo Alfredo J Mansur, Heart Institute - University of Sao Paulo Jose E Krieger, Heart Institute - University of Sao Paulo Alexandre C Pereira, Heart Institute - University of Sao Paulo Luciana Gioli-Pereira, Heart Institute - University of Sao Paulo

Background: Recent reports have described heart failure patients with high Body Mass Index (BMI) presenting lower mortality and rehospitalization rates when compared to patients with Index lower than 25 kg/m<sup>2</sup>. However, remains unclear the real relationship between BMI and heart failure prognosis. Objective: To evaluate the association between anthropometric measures and cardiovascular outcomes in chronic heart failure patients from GENIUS-HF cohort. Methods: Seven hundred patients from GENIUS-HF cohort were evaluated and anthropometric measures (BMI, triceps skinfold, abdominal circumference) were assessed. Inclusion criteria were age between 18 and 80 years and left ventricular ejection fraction (LVEF) of ?50%. Study data will be collected and managed using Research Electronic Data Capture tools. Cardiovascular outcomes (all cause of mortality and hospitalizations) were evaluated every 6-month for 2 years. Results: The overall mortality was 6.8% (47 patients); the composite outcome of death and hospitalization was 17.7% (123 patients) and 1% (7 patients) have been submitted to heart transplantation after one year of enrollment. The patients were predominantly male (67.6%), presented overweight (27.8±5.9) and most of the population analyzed were diagnosed with Systemic Arterial Hypertension (64.5%) and Dyslipidemia (66.5%). Among the anthropometric measures studied, TSF was the only parameter related to death for any cause in 12 months (p = 0.002). Conclusion: Our results suggest that TSF is an independent predictor of one-year overall mortality in our sample, but not BMI.



# Implementation of a prospective, multicenter, interoperable, standardized clinical registry of patients undergoing percutaneous intervention for non-protected left main coronary artery disease

Patrícia Aristimunho, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC) and UNIMED Porto Alegre; Adelia Batilana, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Raphael Boesche Guimarães, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Eduardo Dytz Almeida, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Laura Siga Stephan, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Rogerio Sarmento Leite, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Carlos Antônio M. Gottschall, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); André Luiz Langer Manica, Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC); Clarissa Garcia Rodrigues, Global Research and Innovation Network (GRINN)

# Instituto de Cardiologia do RS - Fundação Universitária de Cardiologia (IC-FUC) and UNIMED Porto Alegre

Background: Left main coronary artery (LMCA) disease is associated with high incidences of morbimortality and medical costs. With the advances of the percutaneous coronary interventions (PCI), it became an option for patients with LMCA disease. Several studies have investigated short and long-term outcomes of those interventions; however, the effectiveness and clinical indications of this therapy are not totally clarified. Thus, there is an urgent need for better control of clinical outcomes related to these patients, based on highly accurate real-world data. Purpose: To describe the implementation of a prospective, multicenter, interoperable, standardized clinical registry of patients undergoing PCI for non-protected LMCA disease. Methods and Results: We carried out the steps: (1) Data standardization in accordance with national and international data elements. Dataset included all applicable data elements published by the AHA/ACC and Brazilian national and demographics datasets; (2) Development of an initial data collection and clinical research workflow; (3) Development of electronic case reports using REDCap and in accordance with the HIPAA privacy rule; (4) Pilot test and validation of the data collection and clinical research workflows and CRFs, (5) Development of automated data quality report using REDCap. All patients over 18 years old undergoing PCI for non-protected LMCA disease are included, from 6 centers in Brazil. Data collection occurs at the outpatient department at the moment of inclusion, 6 months and annually after intervention. Clinical outcomes include all-causes mortality, cardiovascular mortality, non-fatal myocardial infarction, stroke, hospital admissions, visits to the emergency department, restenosis, short and long-term reinterventions and clinic and angiographic characteristics.

APRIL 26-27, 2018 - SÃO PAULO - HOSPITAL SÍRIO LIBANÊS

BRAZILIAN
REDCAPCON

Conclusions: This registry represents a comprehensive database capable to represent real clinical practice favouring research, technology assessment, services management and health policies. By using standardized and interoperable methodologies, it allows for data integration enhancing datasets and leveraging information to help patients with LMCA disease.

# ABSTR



#### Patient Monitoring System of the Pediatric Preventive Cardiology Outpatient Clinic (PREVINA)

Gabriel Nascimento Cândido, IC-FUC; Raquel Potrich Zen, IC-FUC; Daniela Schneid Schuh, IC-FUC; Maira Ribas Goulart, IC-FUC; Karlyse Claudino Belli, IC-FUC; Sandra Mari Barbiero, IC-FUC; Camila Ávila, IC-FUC; Elisandra Furlan, IC-FUC; Marcos Paulo Camboim, IC-FUC; Ângela Bein Picolli, IC-FUC; Lucia Campos Pellanda, IC-FUC.

#### Instituto de Cardiologia - Fundação Universitária de Cardiologia (Porto Alegre)

Introduction: Meticulous collection of clinical outcomes metrics in primary care patients is extremely important to ensure quality care and follow-up. We present a brief description of the electronic case report form (CRF) used to systematic access the data of patients in a cardiology pediatric outpatient service. Methods: The database type used was longitudinal with repeating forms. In total, the database included 14 forms using 445 fields. Automatic fields were used for calculated fields. The pilot implementation for tests occurred from June 2016 to December 2016 and started to be effectively used in January 2017 to present date. Data are collected through an electronic CRF using the REDCap platform. Definition of variables and international standardization of nomenclatures was done to ensure that information entered in the registry will be compatible with international databases. The patient inclusion in the database starts in the first consultation of the patient, who comprehend 7 forms, in order to collect data about the patient's diet, physical activity and mental health, with a transdisciplinary approach. In the subsequent consultations the patients are evaluated for the same team, using 6 to 8 specific forms. Collective training of the team, development of operational manuals for the professionals and monthly reports to actively search for errors in filling out medical records were made. Results: After fourteen months of system implementation, there is data from 96 patients and 27 users. The inconsistencies in patients' medical records were reduced, thus avoiding loss of information pertinent to the consultations. Conclusion: This system allows the rapid tracking of data, results and interventions of the patients, contributing both to an evaluation of the effectiveness of outpatient care as well as to future research in the field.



#### Rational for online monitoring of health data indicators using REDCap and R

Guilherme Azambuja, IC-FUC; Karlyse Claudino Belli, IC-FUC.

#### Instituto de Cardiologia - Fundação Universitária de Cardiologia (Porto Alegre)

Introduction: Research electronic data capture (REDCap) is a web application for rapid development and deployment of electronic data capture tools. R is a free software environment for statistical computing and graphics, and an integrated suite of software facilities for data manipulation, calculation and graphical display. Its integrated use allows the storage, management, analysis and use of the results as support for health decision making. Purpose: This study assesses a electronic and systematic method for demonstrate in-hospital or out-hospital results, in a dashboard available online as a website, with data stored in a REDCap electronic database. Methods: This procedure represents a systematic method for read, analyze and use clinical data as indicators of quality health care. Data stored in 'REDCap' databases will be accessed using the Application Programming Interface (API). The 'redcapAPI' package will process of accessing to REDCap data with options to prepare an analysis-ready data set. The 'readR' package will be used to read a database, 'survival' package will to perform simulations, and 'ggplot' and 'plotly' for generate graphics. Data manipulation and the interactive user interface of the results will use the 'shiny' package. Expected results: This system will allow the tracking of patients' data and the mining of the institutional database for future research. This will provide a dashboard for health managers and patients to access in real time the performance of the respective health institutions linked to the databases. Conclusion(s): The development of syntaxes that integrate access to REDCap databases with data analysis and R development will enable the deployment of dashboards to access healthcare outcomes, increase the use and transparency of institutional results.



#### REDCap use for 'Lipp Adult Stress Inventory' questionnaires of stress evaluation

Luciane Marina Léa Zini Peres, IC-FUC; Vitória Recuero Fagundes, IC-FUC; Carine schmidt, IC-FUC; Aline Silva Lima, IC-FUC; Marcia Moura, IC-FUC; Karlyse Claudino Belli, IC-FUC.

#### Instituto de Cardiologia - Fundação Universitária de Cardiologia (Porto Alegre)

Introduction: Data capture of clinical outcomes from patients may help improvements in quality care, however it is difficult to establish a data collection routine that should not hinder or increase the work time of health professionals. Purpose: This study assesses a electronic and systematic method using REDCap for evaluation of stress in an ambulatory of cardiology. Methods: This procedure represents a systematic method for application of padronized questionnaires of stress evaluation in REDCap. A platform was designed for collecting data during an interview and automatically calculate the results of questionnaires. All data could be collected and recorded using mobile devices or desktop, during psychological examination. After that, all data are ready for any analyses for quality control or research projects. Results: The 'Lipp Adult Stress Inventory' was designed based on 53 questions, composing 53 categorical variables in REDCap database. The questionnaire is composed by three phases, which has multiple answers categorize with choices of yes or no. For calculations we used: branching logic, which defines one point for each symptom 'checked'; and 'sum' and 'if' commands were used to add up the amount of reported symptoms for each phase. After that, all sums automatically done immediately in the end of filling. Also, all percentages are ready to classify each patient in real time at the end of questionnaire application. We executed a pilot test of electronic questionnaire (sample: health students and secretaries), spending 3.39 minutes (mean) interviewing each one. All calculations worked well. Conclusions: A REDCap platform could be used for interview and gathering data, with automatic standardized rules for questionnaires calculations and classifications of patients according 'Lipp Adult Stress Inventory'. The REDCap system allows the tracking of patients' outcomes and generate an institutional database for future research.



Implementation of a screening system to recruit and randomize children and adolescents with advanced cancer and their parents for the PediQUEST Response Intervention Study

Alvaro Ciganda, IECS; Rocío Rodriguez, IECS; Luz Gibbons, IECS; Maria Luisa Cafferata, IECS; Laura Gutierrez, IECS; Candela Stella, IECS; Veronica Dussel, IECS/DFCI; Joanne Wolfe, DFCI; Eduardo Bergel, IECS; Mabel Berrueta, IECS.

IECS: Instituto de Efectividad Clinica y Sanitaria (Argentina); DFCI: Dana-Farber Cancer Institute.

Background: The PediQUEST Response Intervention Study is a multisite, parallel, randomized controlled trial whose objective is to evaluate whether the Pediatric Quality of Life and Evaluation of Symptoms Technology Response to Pediatric Oncology Symptom Experience (PediQUEST Response) intervention improves pediatric oncology patient and parent outcomes compared to usual care in children and adolescents with advanced cancer. The study will be conducted in four hospitals in USA. Objective: To create system for the screening, recruitment and randomization of children and adolescents with advanced cancer and their parents and guide the staff work-flow. Methods: The process requires numerous steps in order to achieve the final dyad recruited: 1) check eligibility criteria by research coordinator (RC), 2) validate eligibility criteria by site principal investigators (PI), 3) obtain opt-out from the primary oncology, 4) approach the family several times as needed and re check the eligibility before enrollment by RC, 5) enroll the dyad by RC, 6) capture baseline clinical information by RC, 7) select pre randomization patients after a running period by the project manager (PM) and 8) randomize eligible dyads by RC. We created an unified REDCap based system employing six essential features: 1) piping, calculated variables and branching logic to avoid complete out of sequence forms and validate data among different forms, 2) repetitive forms to register the approach process, 3) stratified randomization by age group and data access group, 4) API and data entry trigger to notify the next responsible person in the process by email after a form is complete and to copy the last instance of approach form into a no repetitive form, 5) reports to monitor the process and 6) data access groups and role-based access control. Conclusions: Designing a solution incorporating REDCap allows to conduct and monitor a complex process that involves several stakeholders and roles.



A data management software application - REDCap - in research to assist the prevention practices of a specialized service in patients living with HIV / AIDS (SEAP), 2017, Sao Paulo, Brazil

Picone C.M¹; Nisida I.V.V²; Avelino-Silva V.H.², Vasconcelos R.P², Pereira C3, Noronha N1, Alves APPS1, Camargo LA3, Silva DAC3, Pimentel GS4, Alves FS5, Gasparini SM4, Segurado A.A.C6. ¹Nurse, 2Doctor, 3Psychologist, 4Social Worker, 5Computer Technician and 6Director do Serviço de Extensão ao Atendimento de Pacientes vivendo com HIV/Aids (SEAP) - Divisão e Departamento de Moléstias Infecciosas e Parasitárias (DMIP), Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo- HCFMUSP, São Paulo, SP, Brasil.

Divisão de Moléstias Infecciosas e Parasitárias (DMIP), Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo- HCFMUSP, São Paulo, SP, Brasil.

Introduction: The SEAP of HCFMUSP, active since 2014 in the city of São Paulo, currently has 3200 adult patients living with HIV. It also offers preventive care to users of the Brazilian health system, for Pre-Exposure Prophylaxis (PReP) and Post-Exposure Prophylaxis (PEP) offering rapid testing for HIV, syphilis and hepatitis B and C. In its performance as a tertiary academic service, tools were found to manage information, mainly focusing on prevention and adherence of patients to the follow-up, aiming at excellence in assistance and conducting operational research for the evaluation of health policies. Objectives: To describe the experience of a university service specialized in the care of patients living with HIV, in the use of REDCap tool in parallel to the assistance service. Method: Observational descriptive study of REDCap utilization by the multidisciplinary prevention team. Computerized questionnaires (CQ) were developed for the rapid test protocols (HIV, syphilis, hepatitis B and C) and PEP prescription. Results: CQs were applied by professionals to 1335 adults from January to December of 2017, with a percentage of 72.2% males, a mean age of 31 years old (SD = 10). Rapid testing was positive in: 1.7% HIV; 30.6% syphilis, 20.5% hepatitis B and 7.2% hepatitis C. PEP was prescribed in 7.3% of the cases. Conclusion: REDCap was proven very useful to expand access to information to the multidisciplinary team, sharing knowledge, streamlining the data analysis and contributing to the operational research support in the unit.



# Changes from a offline to an online system of data collection (REDCap) for research in congenital cardiopathies

Vitória Recuero Fagundes, IC-FUC and UFCSPA; Maíra Ribas Goulart, IC-FUC; Karlyse Claudino Belli, IC-FUC; Daniela Schneid Schuh, IC-FUC; Sandra Mari Barbiero, IC-FUC; Lucia Campos Pellanda, IC-FUC and UFCSPA.

## Instituto de Cardiologia - Fundação Universitária de Cardiologia and Universidade Federal de Ciências da Saúde

Introduction: Excel and SPSS have limited control over quality of data entered in their spreadsheets, with security level limited, and REDCap is an online platform designed to store and manage databases. Objective: Describe a process of migrating from an offline database to an online platform (REDCap). Methods: We used a database with 474 patients, 157 variables (64 categorical, 93 numerical). Database migration process involved 4 steps using Google Drive, SPSS and REDCap. 1st step - a original database (SPSS) was our reference file to design a standardized data dictionary for REDCap; 2nd step - download (.csv) and upload a data dictionary to REDCap, checking possible inconsistencies; Step 3 - export SPSS database to Google Drive (to review/standardize variables), and import as .csv format to REDCap; Step 4 - added a new case report form (50 variables) to add/start a new data collection process. Results: It was a secure change, without losses of data between/during all steps. It allowed to identify outliers and variables without a previously established data collection standard. We improved standardization of collection for all variables and reviewed all existing categories and numerical limits. Design a new CRF (4th step) was easy and faster. It was elaborated directly inside REDCap, reducing chances of forget standardization important characteristics for each type of variable. Use of REDCap allowed: control of each actions from users; greater interaction in data revisions; faster typing of questionnaires (more than one user typing at the same time); automatic reporting for missing data control and typing errors; easier export of data to statistical programs. Conclusion: The process of database change for REDCap made it possible to analyze a database more critically, detecting failures. We have expanded the use of data and, in the future, will integrate new research projects on congenital cardiopathy into a single database.



Integrating data collection into in-hospital workflow and electronic health records with clinical outcomes for quality indicators and research

Leonardo Hennig Bridi, IC-FUC; Karlyse Claudino Belli, IC-FUC; Renato Abdala Karam Kalil, IC-FUC.

#### Instituto de Cardiologia de Porto Alegre

Background: REDCap is a workflow methodology and software designed for rapid development and deployment of electronic data capture tools to support clinical research. Meticulous collection of clinical outcomes data in patients undergoing surgery are important to ensure quality care. On the other hand, it is not easy to establish a routine in which data collection does not overload the work time of health professionals. Objective: This study assesses an electronic and systematic method using REDCap for gathering postoperative data and generate an automatic medical report on adult patients undergoing cardiac surgery. Methods: The electronic data collection was initiated in October 2015, patients continue to be actively enrolled, and follow-up data continue to be collected. This procedure represents a systematic method for documentation of surgical management and follow-up of patients. For consistency and ease of medical report, as well as prescription, this method generates a standardized text which is copied for institution's electronic health record system. All data are recorded using mobile devices in bedside, during medical examination. After that, in a desktop, the physician copy and paste an automatic generated text with his medical record for institutional database. Results: During two years that this process has been in place, outcomes data have been collected on 1544 patients at one time point to create an institutional database. This system allows the tracking of patients' outcomes data and the mining of the institutional database for future research. It causes less mistakes avoiding double collection from the same patient and data transcription errors. Furthermore, is possible to have the descriptive results of all patients in the same moment of completion each new case. Conclusion: A REDCap platform could be easily used for gathering postoperative data and generate an automatic medical report in real time for inpatients. Providing an institutional database for future research.



#### REDCap and Health Outcome Measurements programs: a perfect match

Felipe Elias Cardoso dos Santos, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Teresa Cristina D. C. Nascimento, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Amanda Danieletto Ruiz, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Lívia do Valle Costa, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Debora Santos de Oliveira, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Leandro de Moraes, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Eduardo Fernandes Abrantes, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Luiz Fernando Lima Reis, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Antonio Eduardo Antonietto Junior, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês; Carla Bernardes Ledo, Sociedade Beneficente de Senhoras Hospital Sírio-Libanês.

#### Sociedade Beneficente de Senhoras Hospital Sírio-Libanês

At the beginning of 2017, the Sírio-Libanês Hospital created an area dedicated to the implementation and management of programs aimed at evaluating the clinical outcomes of the institution's patients. In this context, the Standard Sets defined by ICHOM (International Consortium for Health Outcome Measurements) were adopted, and for pathologies where these are not available, specific protocols have been developed by specialists in the respective areas. The use of REDCap was initially considered due to the set of features offered by this platform. We can highlight the key characteristics for clinical outcomes management: rapid implementation of data collection forms, allowing the prototyping and agile homologation of new programs; allows continuous and secure modifications of production databases; able to collect longitudinal data; a built-in project calendar and scheduling module for managing patient's follow-up; detailed configuration of user permission levels; audit trails for tracking data manipulation and user activity; data-quality tools; a robust set of features to send and manage surveys among other features. Despite the flexibility offered by REDCap, several ICHOM programs present complex timelines for patient follow-up and implementation decisions were fundamental to optimize the use of REDCap. Thus, additional solutions have been used to support the visualization and export of data in specific formats intended for the analytical stage between different institutions. In this sense, Business Intelligence applications have been used for data consolidation and visualization, and Python scripts have been written for data extraction and transformation steps. The purpose of this work is to describe the solutions adopted by the Sírio-Libanês Hospital for REDCap use as a primary tool for collecting and managing data in Clinical Outcomes programs.



### Teaching about REDCap for health professionals: could it promote collaboration between institutions?

Karlyse Claudino Belli, IC-FUC; Jacqueline Vaz Alencar, IC-FUC.

#### Instituto de Cardiologia de Porto Alegre

Background: Inclusion of REDCap as content in learning of health professionals could enable one practical demonstration of research importance on educational tripod (education - research assistance). REDCap is a software with international use and learning about its use could promote a network collaboration between institutions that work with this. Objectives: To report some cases about REDCap use in educational institutions with regard to collaboration networks. Methods: Case report about teaching and use of REDCap as part of educational content for health professionals (graduation and postgraduate). Profile of institution: a hospital of Cardiology that offers professional education (nursing, physiotherapy, medicine, nutrition, psychology; at level of residence, post-graduation lato sensu and stricto sensu). Results: Were collected some reports about REDCap use from students who spent a period of their studies outside Brazil to do internships (or part of their master's / doctorate degree) in institutions abroad. In these countries, they had to work on databases already implemented in REDCap and/or they discovered that REDCap was in implantation phase, being able to make presentations about how was their experience with REDCap use in Brazil. In addition, we also had an experience to plan and execute a multicenter project using REDCap. In this case, main centers that collaborated were centers which former students (from our center) are working now and already knew REDCap during their studies inside our center. Training for students (during graduation/post-graduation) should be part of actions to promote a network of collaborators between the institutions at national and international levels. Professionals already familiar with REDCap would present less difficulties to initiate collaborations in future projects that will use a same database. Conclusions: The inclusion of content involving REDCap as a collaborative research tool among national / international institutions could improve a network of collaborations for future studies.



#### Implementing a clinical multicenter study on treatment adherence: the ADHERE BRASIL Study

Fernando A.B. Colugnati, Medicine School/ UFJF; Elisa de Oliveira Marsicano, Nursery School/ UFJF; Barbara Bruna Abreu de Castro; NIEPEN/ UFJF; Helady Sanders-Pinheiro, Medicine School, Renal Transplantation Unit, University Hospital/ UFJF; on behalf of the ADHERE Brazil Study Consortium

#### Faculdade de Medicina/ Universidade Federal de Juiz de Fora

Non-adherence to immunosuppressive medication is a prevalent risk factor for negative clinical and economic outcomes in kidney transplantation (KT) and studying its prevalence and multilevel correlates in Brazil will contribute to a gap in transplantation knowledge both locally and internationally. The ADHERE BRASIL Study aimed to assess the prevalence and variability of nonadherence to treatment in adult Brazilian KT patients and to assess the multi-level correlates of immunosuppressive medication. It is an observational cross-sectional study, comprising 20 KT centres, covering all geographical regions and different service sizes, collecting data from 1107 patients. All research management were implemented using REDCap, using two different projects, one for centre data and the other for patient individual data. More than 30 health professionals were trained in personal meetings and were given support material in booklets as well as helpdesk by phone and e-mail. The use of a standardized data platform for data entry were well received by all centre managers, and their teams. Despite the continental size of Brazil, and some connection problems in the centres and in the main webserver, the sample completion was considered optimal. Critical analysis showed that typing errors and misleading information were minimal, having missing data that were actually not available even in the centres, according to a check follow up by phone. The use of REDCap was considered a significant tool to achieve the study goals in terms of quantity and quality of data, preserving centre and patient information privacy and improving data reliability.



