The Biomedical Informatics Infrastructure for Translational Research at MUSC

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Co-director, BMIC
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Outline

- Biomedical Informatics for Translational Research
- EHR Data for Research
- Research Permissions
- Data Capture
- Epic Services
- Other Informatics Tools and Services
- Data Science Research and Education

Learning Objectives

- What are the components of the biomedical informatics infrastructure for translational research?
- How to access and leverage the informatics resources and services at MUSC?
- Learn about some examples of data science and AI research projects.

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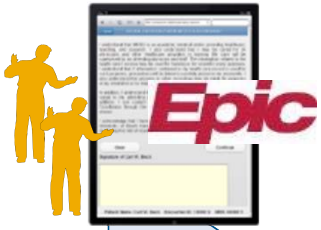
Translational Research Informatics Infrastructure

Statewide IRB Reliance

Patient Engagement
& Recruitment

Research Permissions



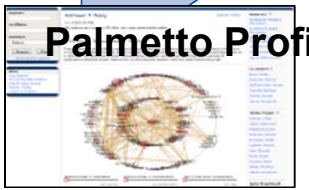
REDCap
Research Electronic
Data Capture

RDW (MUSC)
HSSC CDW (Statewide)
& Master Patient Index

NLP and Machine Learning

CTSA Services, Budgeting,
Epic Integration for Clinical Trials

Statewide Clinical Trial
Feasibility & Cohort Analysis



Research Collaboration

The Biomedical Informatics Center (BMIC)

Themed around the Learning Health System

- a Learning Health System *in which*
  - **Every patient** has the opportunity to benefit from research
  - **Every clinician** has their cohort of patients from which to learn
  - Every scientist has the human-derived **materials** needed for study
  - Every interdisciplinary team can **influence the health system** to learn from it

Leadership

Dr. Leslie A. Lenert
Director

Dr. Jihad Obeid
Co-director

BMIC Faculty: Academic Home in DPHS

Leslie Lenert, MD, MS
Professor,
CRIO
Director, BMIC

Jihad Obeid, MD
Associate
Professor
Co-director

Lewis Frey, PhD
Associate
Professor

Alexander Alekseyenko, PhD
Associate Professor

Brandon Welch, PhD
Assistant Professor

Vivienne Zhu, MD, MS
Assistant Professor

Stephane Meystre, MD, PhD
Associate Professor

Part time

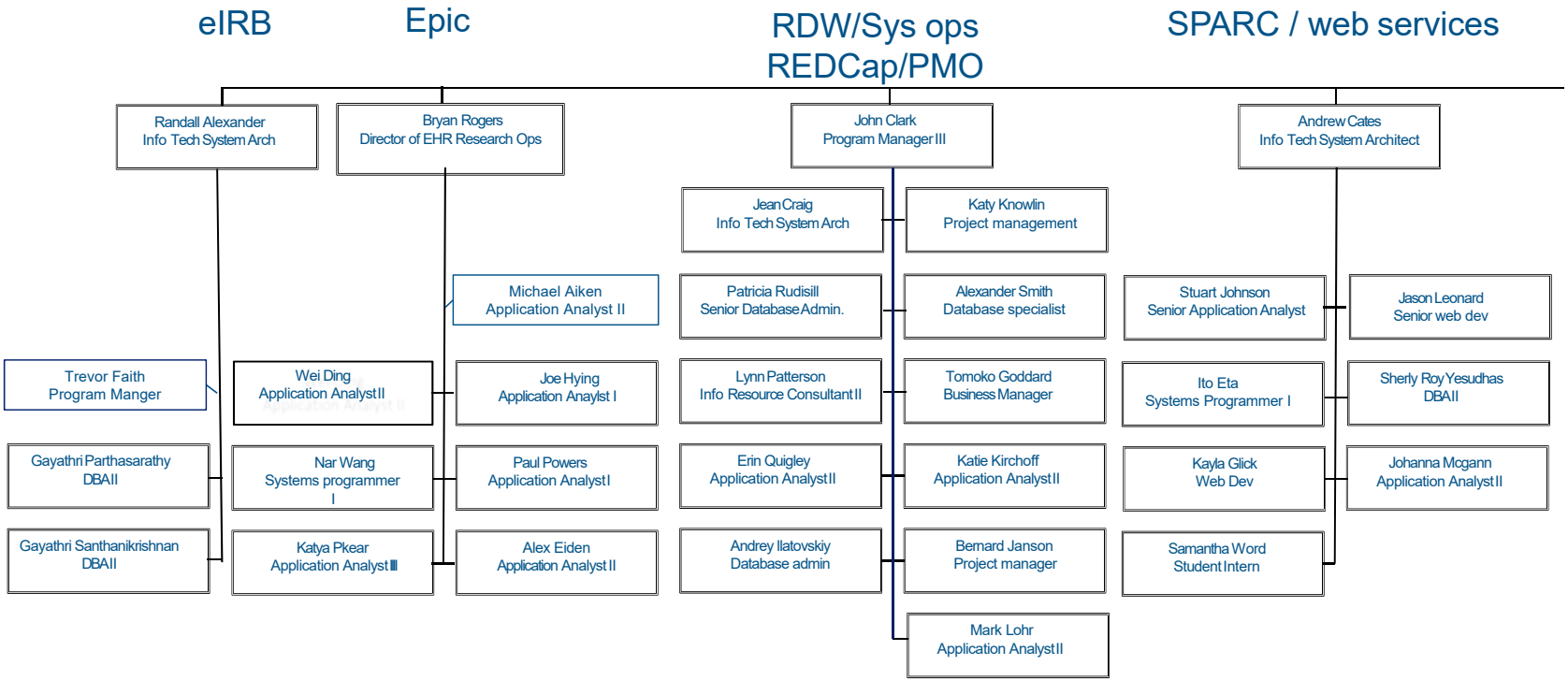
Christine Carr, MD
Professor

Christopher Metts, MD
Assistant Professor

THE ONLY BIOMEDICAL INFORMATICS PROGRAM IN SC

MUSC Medical University of South Carolina
Changing What's Possible | MUSC.edu

BMIC Operations Teams



SPARC Request: https://sparc.musc.edu/

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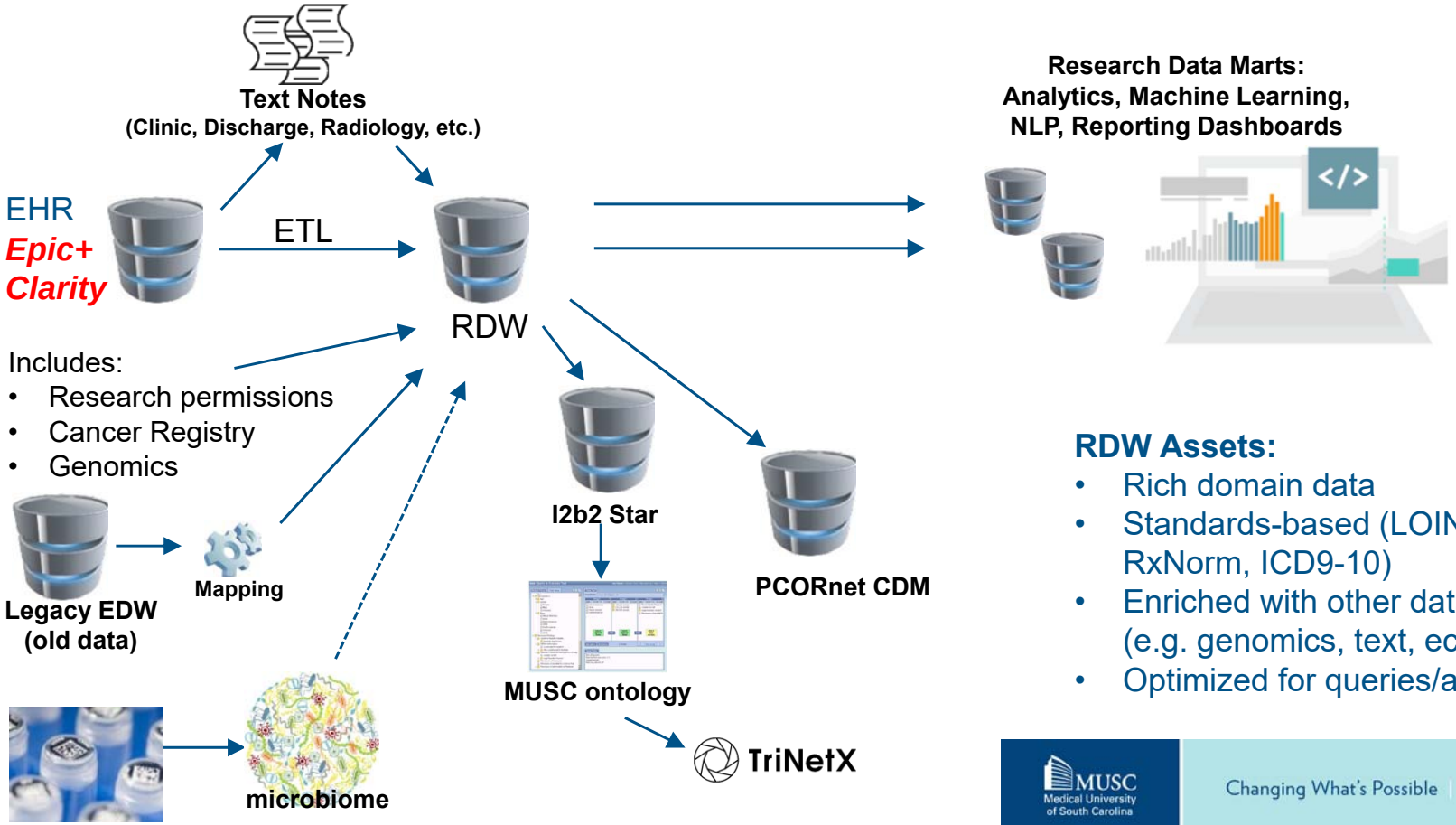
MUSC Research Data Warehouse (RDW)

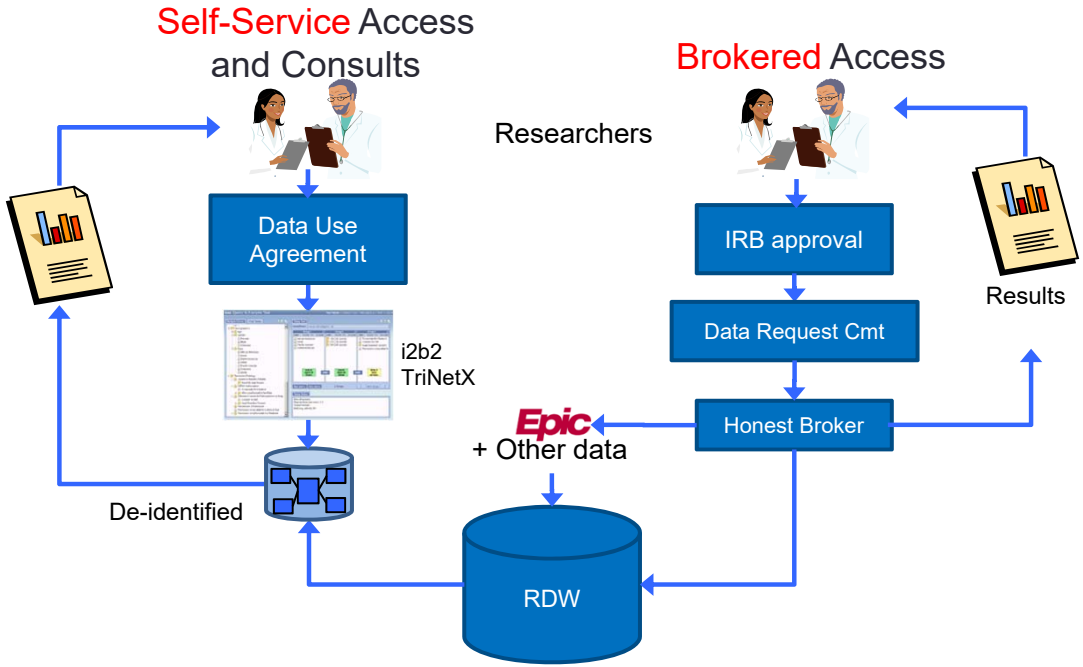


RDW Assets:

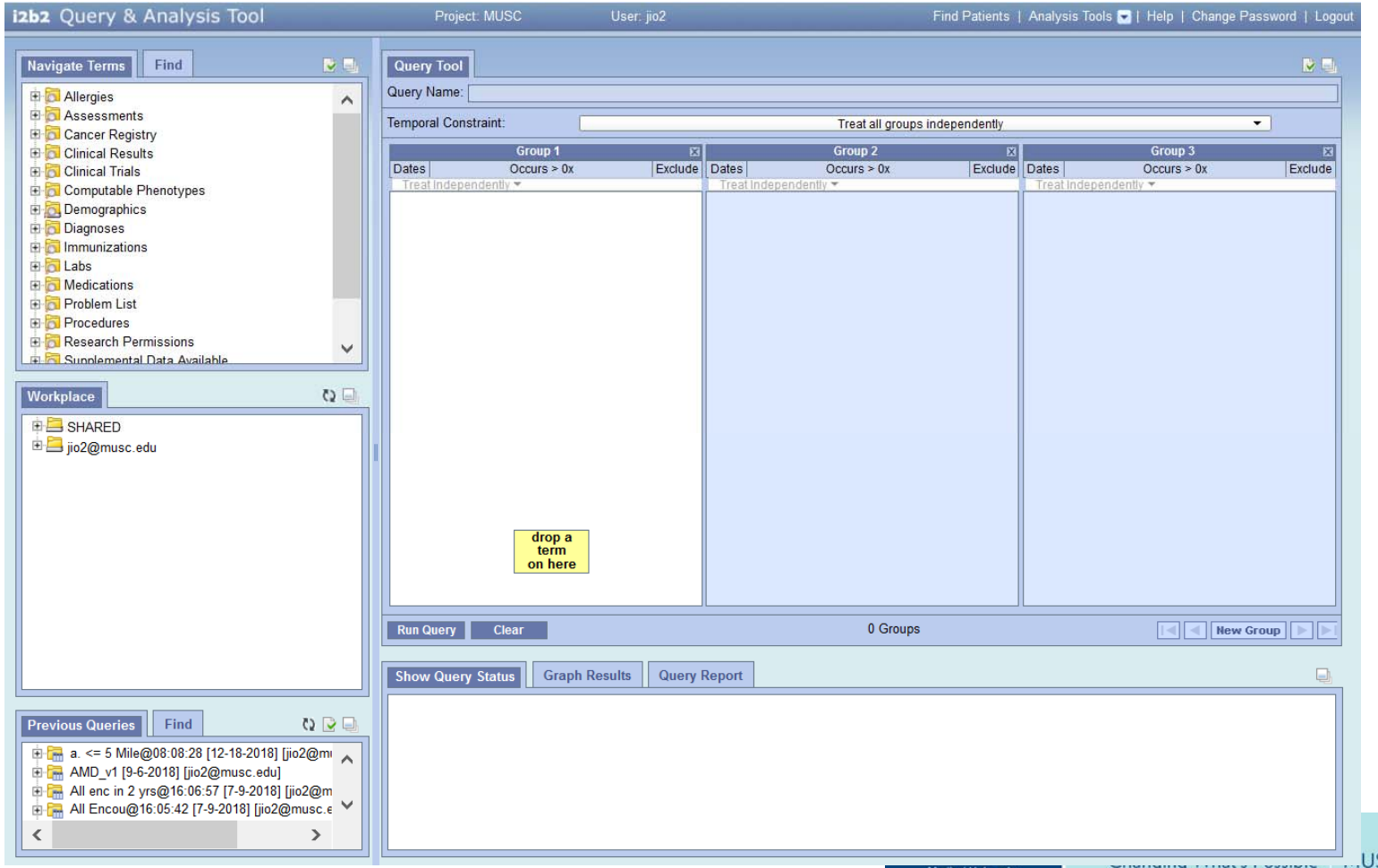
- Rich domain data
- Standards-based (LOINC, RxNorm, ICD9-10)
- Enriched with other data sources (e.g. genomics, text, ect.)
- Optimized for queries/analytics

Governance of EHR Data for Research (IRB Approved)

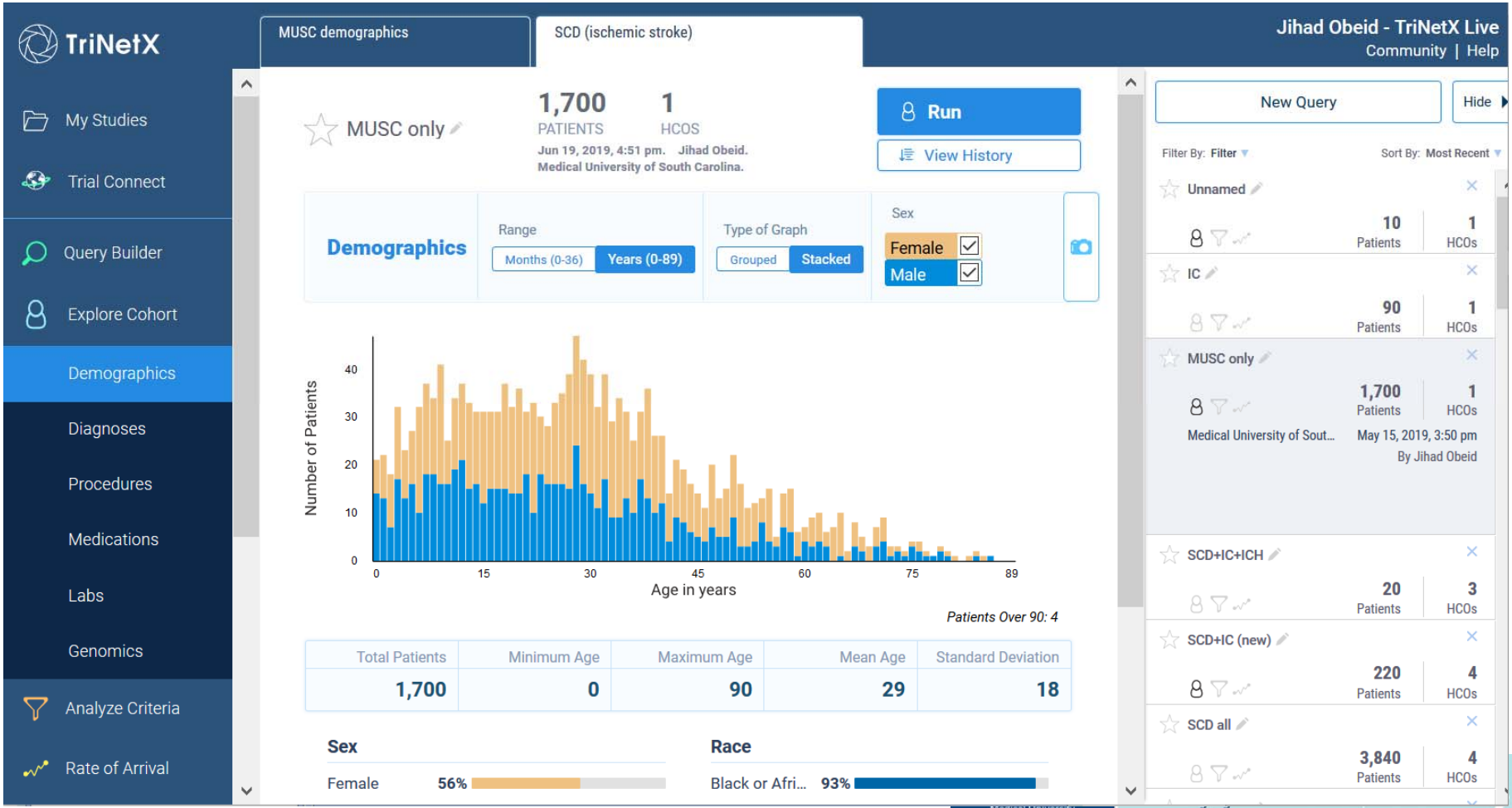
Including data consults and honest broker for identified data access



i2b2 at MUSC: https://i2b2.musc.edu/



TriNetX at MUSC: https://live.trinetx.com

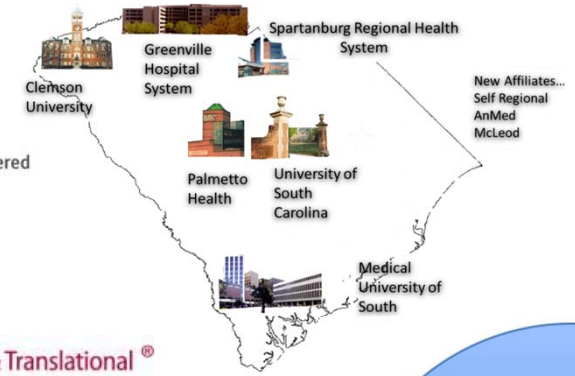


Collaborative Networks

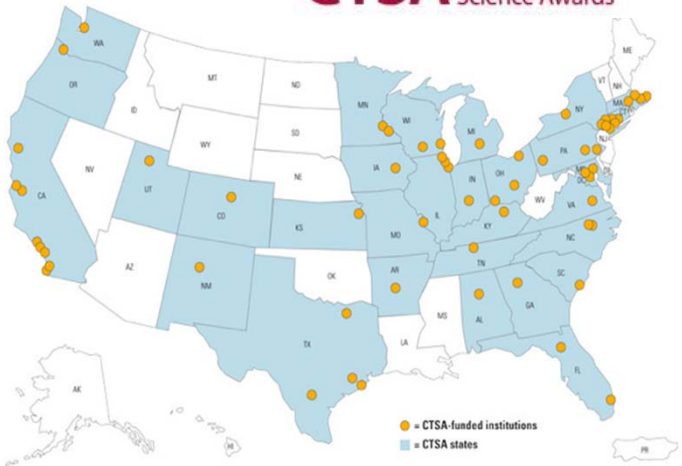
pcornet® The National Patient-Centered Clinical Research Network

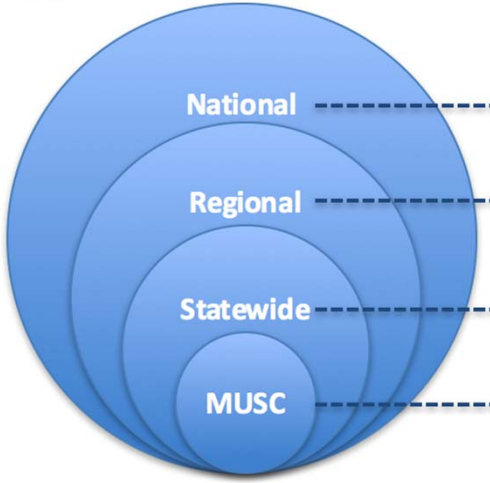
STAR Stakeholders, Technology, and Research CRN

CTSA® Clinical & Translational Science Awards



HEALTH SCIENCES SOUTH CAROLINA





Networks

ACTNetwork SHRINE i2b2
PCORnet

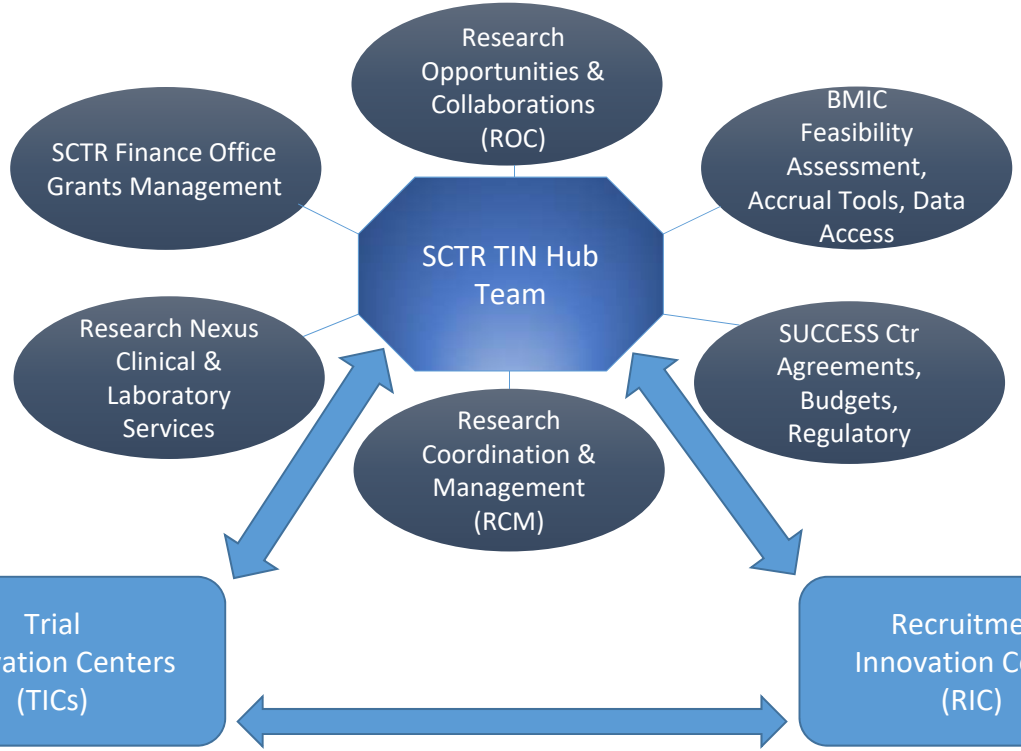
Carolinas Collaborative,
MidSouth, Southeastern SHRINE

HSSC i2b2

Local RDW, i2b2, SD, Other...

Network Capacity (SCTR)

Dr. Marc Chimowitz
Program Director



Signe Denmark, MS, CCRP
Associate Director,
Research Opportunities & Collaborations

Aim 1: Optimize processes to operationalize TIN clinical trials
Aim 2: Train and assist clinicians for multisite clinical trials
Aim 3: Enhance novel recruitment strategies: NLP, telehealth, community…

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MUSC Research Preferences

Questionnaire in Epic MyChart & in clinic

Biobank

Retention / Disposal and Use of Blood, Body Fluids, or Tissue.

I understand that any blood, body fluids or tissues normally removed from my body by MUSCHealth, including its hospital(s), physicians and staff, in the course of any diagnostic procedures, surgery, or medical treatment that would otherwise be disposed of may be retained, and used for research, including research on the genetic material (DNA) or other information contained in those tissues or specimens. I acknowledge that such research by MUSCHealth, may result in new inventions that may have commercial value and I understand that there are no plans to compensate me should this occur, regardless of the value of any such invention. I understand that any research using these leftover specimens or tissues will be done in a way that will not identify me. If I have questions, I should call (843) 792-8300 or visit http://www.muschealth.org/clinical-trials/.

- I AGREE to have my leftover blood, body fluids or tissue used for future research studies.
- I do not agree to have my leftover blood, body fluids or tissue used for future research studies.
- I am not ready to make a decision at this time

Contact

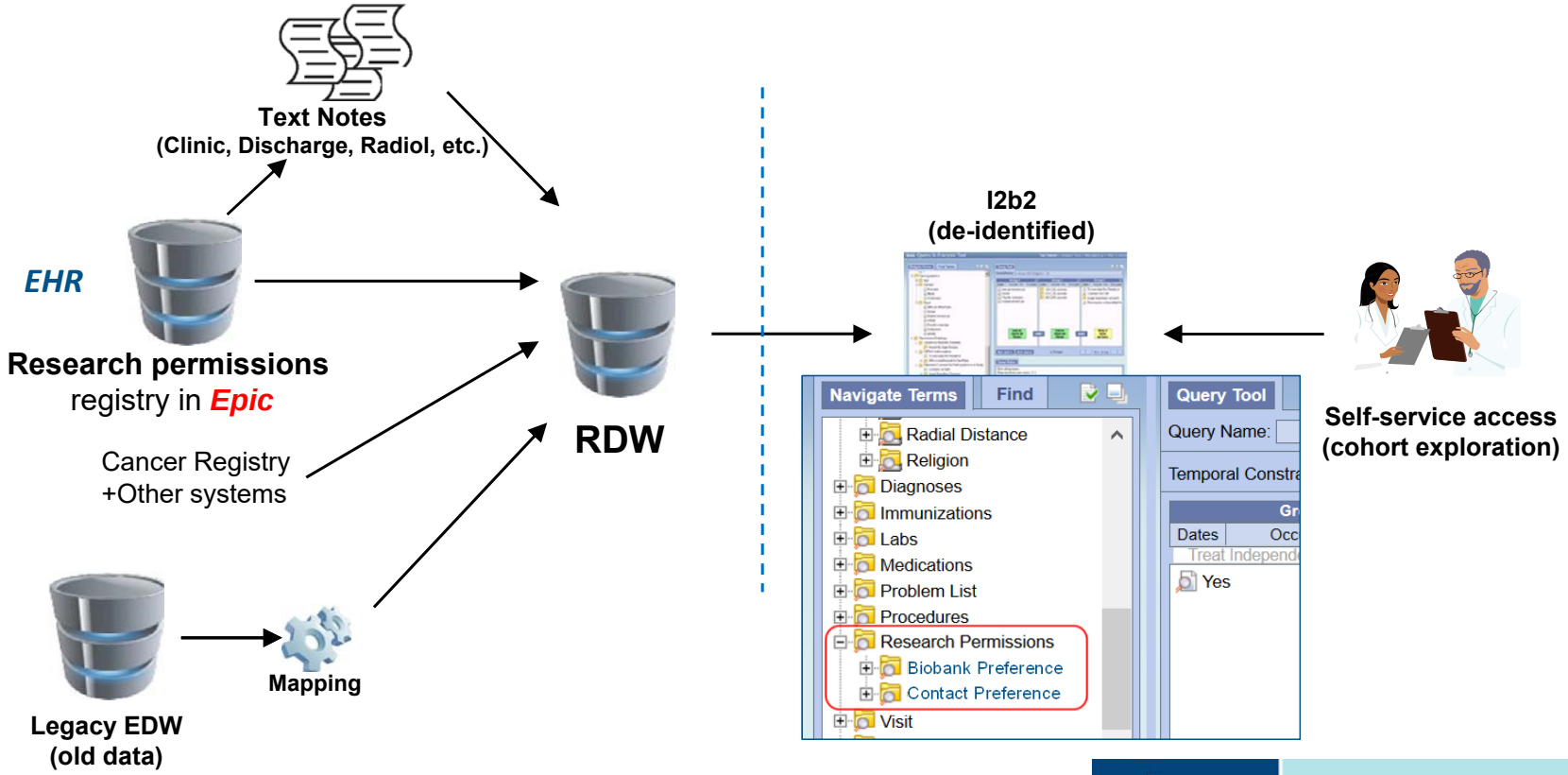
Preference for Contact by Research Studies.

I understand I may be contacted about future research studies at MUSC for which I may be eligible. If I have questions, I should call (843) 792-8300 or http://www.muschealth.org/clinical-trials/

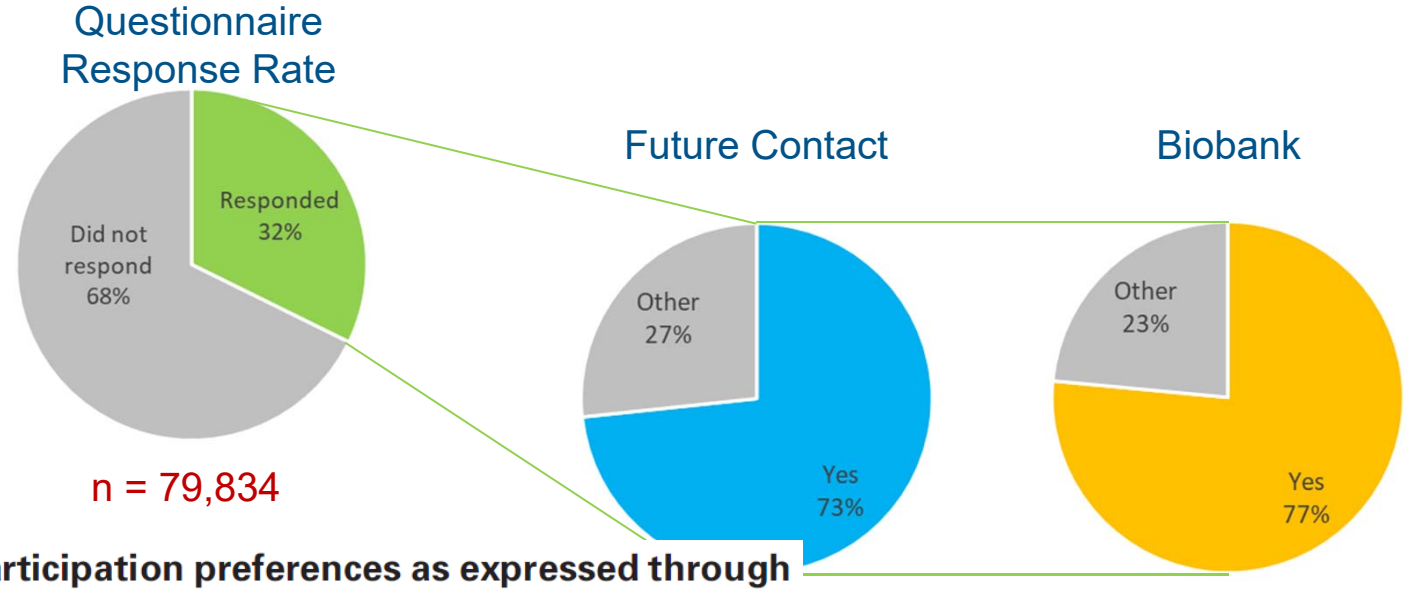
- I AGREE to be contacted about future research studies.
- I do not agree to be contacted about future research studies.
- I am not ready to make a decision at this time.

If at any time you would like to update your research preferences, you may modify them from the Questionnaires section…

Research Permissions Registry Expressed in i2b2



Response Breakdown



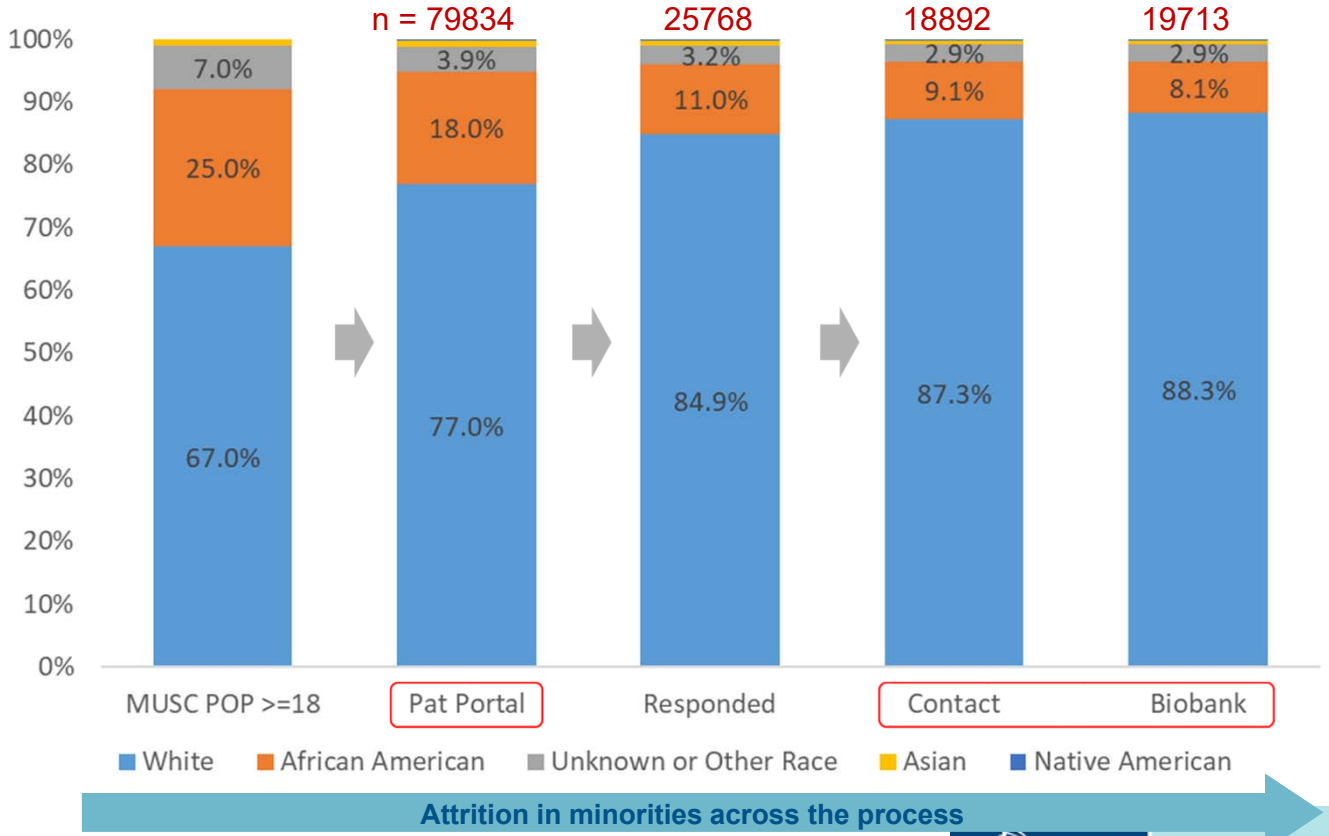
n = 25,768 (in 2016)
(in 5/2019 > 54k)

Research participation preferences as expressed through a patient portal: implications of demographic characteristics

Jihad S. Obeid,[1] Azza Shoaibi,[1] Jim C. Oates,[2,3] Melissa L. Habrat,[1] Chanita Hughes-Halbert,[4] and Leslie A. Lenert[1]

JAMIA Open, 1(2), 2018, 202–209
doi: 10.1093/jamiaopen/ooy034

Race Breakdown: across patient portal and research permissions



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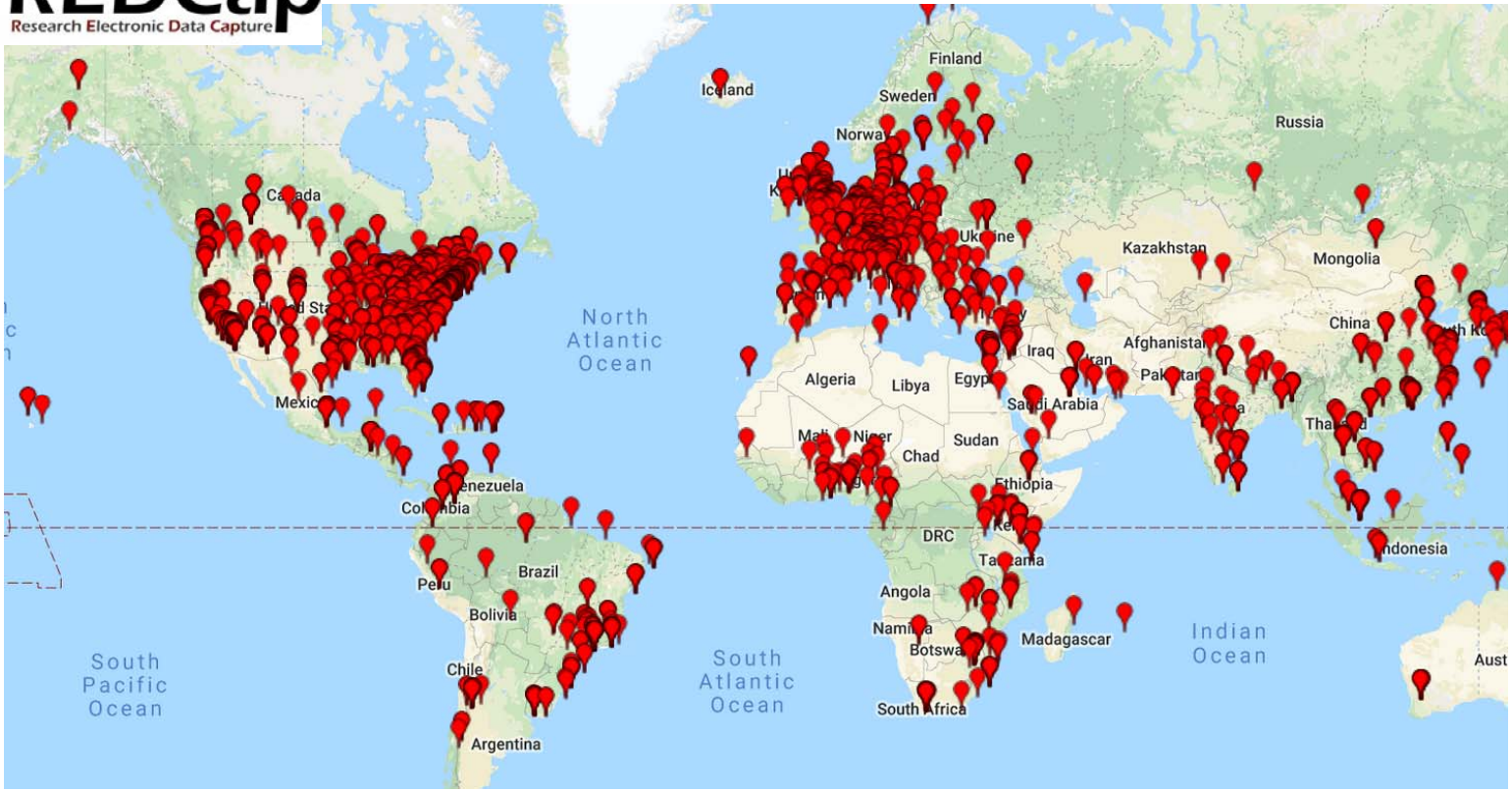
REDCap
Research Electronic Data Capture

- Electronic Data Capture for research studies:
  - Allows you to construct case report forms (CRF) online
  - Enter data via the web or mobile app
- Allows design of surveys
  - Collect data directly from participants
  - Can send links to specific individuals or via MyChart or online link
- Allows you to import/export data to statistical packages (SAS, R, SPSS) and CSV/Excel
- Easy to share data dictionary
- Secure web interface; Data integrity; Data center security and backup; HIPAA compliance

REDCap
Research Electronic Data Capture

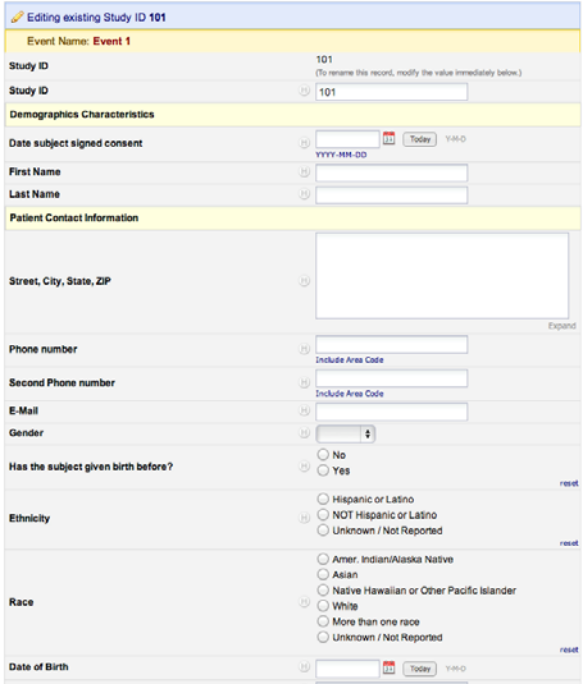
Consortium >3800 Members



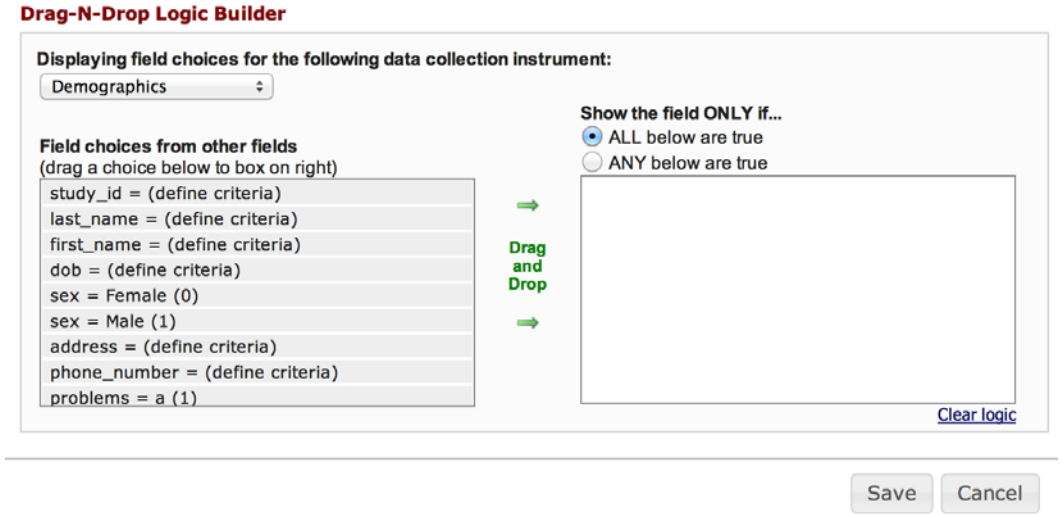
https://projectredcap.org/about/consortium/

REDCap
Research Electronic Data Capture

Example Form



Branching Logic



REDCap
Research Electronic Data Capture

Supports Consent/Assent Forms + electronic signatures

Alternative Procedures:
If you do not want to participate in this study, please inform your counselor and you will continue with typical counseling sessions.

Confidentiality:
All of the information provided in this survey will remain completely anonymous and confidential. All information will be coded with a number so that names will not be present on any of your records. All of your information will be stored securely on password protected computers. Only study personnel will have access to your information unless we learn of clear and imminent danger to you or someone else, reasonable suspicion that a child or elder is currently being abused, or by court order.

Person to Contact:
For more information or to obtain answers to any questions, please contact Dr. Mark Weist, professor at USC and lead for the study at (803)777-0449; weist@mailbox.sc.edu or Research Coordinator, **Name, phone number, email** at any time. Please also visit our website, **website** link, for more information.

Institutional Review Board:
If you have questions about you or your child's rights i
Manager, Office of Research Compliance, University o
414D, Columbia, SC 29208, phone: **phone number** or

Consent:
By signing this form, I confirm that I have read and und
given the opportunity to ask questions or request more i
voluntary and that I have the opportunity to withdraw a

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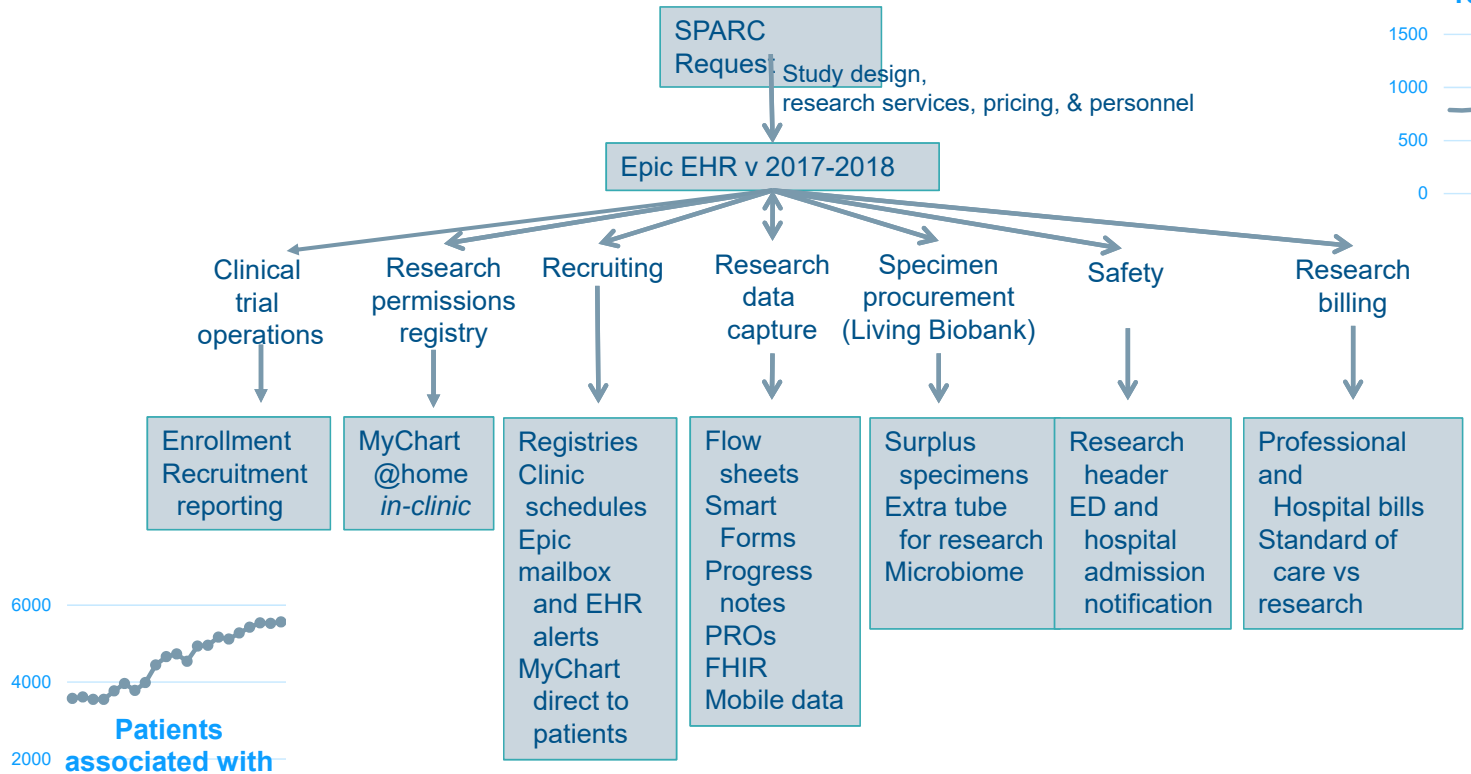
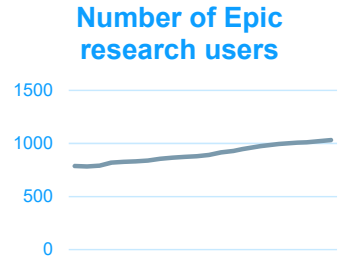
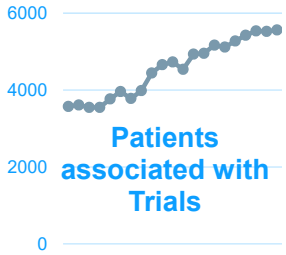
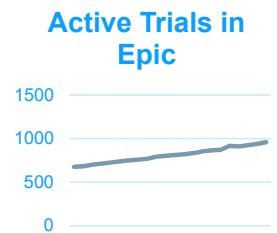
Epic Research Team

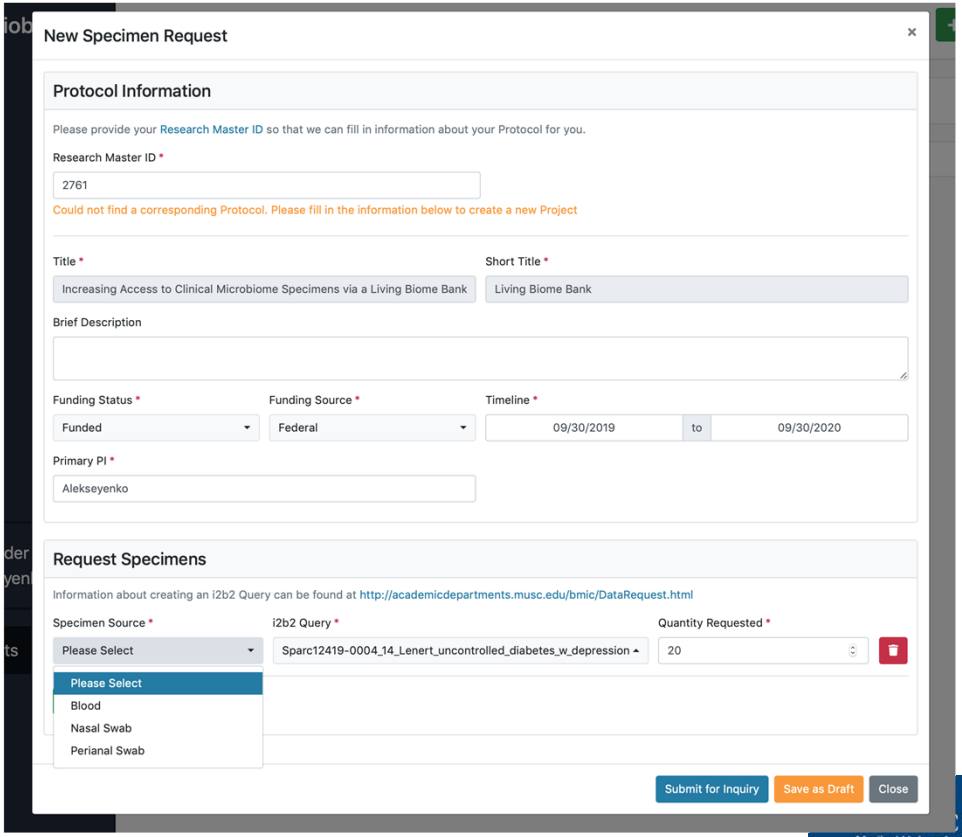




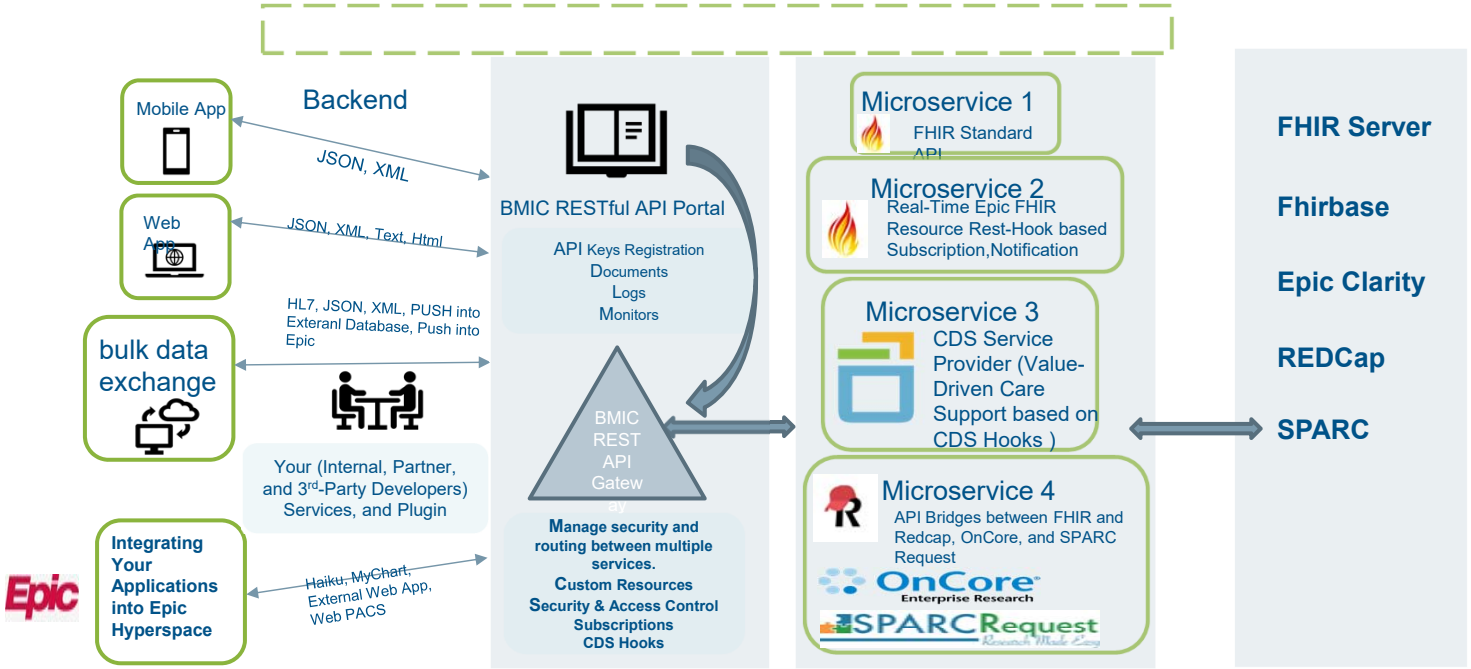




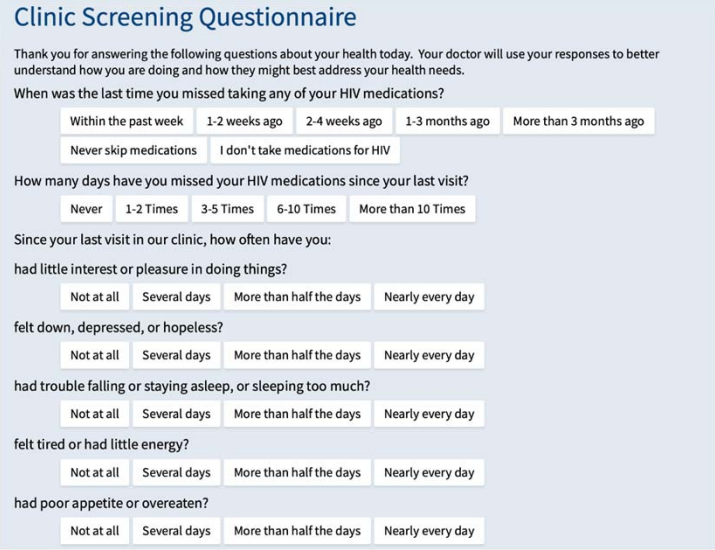
Living Biobank: Specimen/data request submission

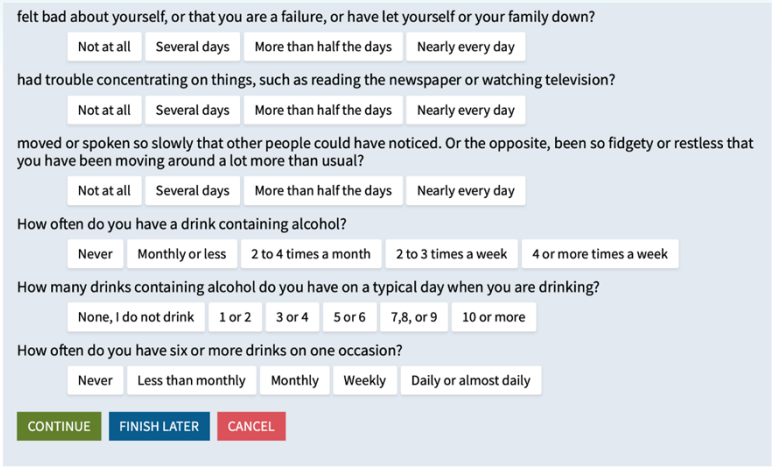


BMIC Gateway Streamlines Two-way Integration with Epic



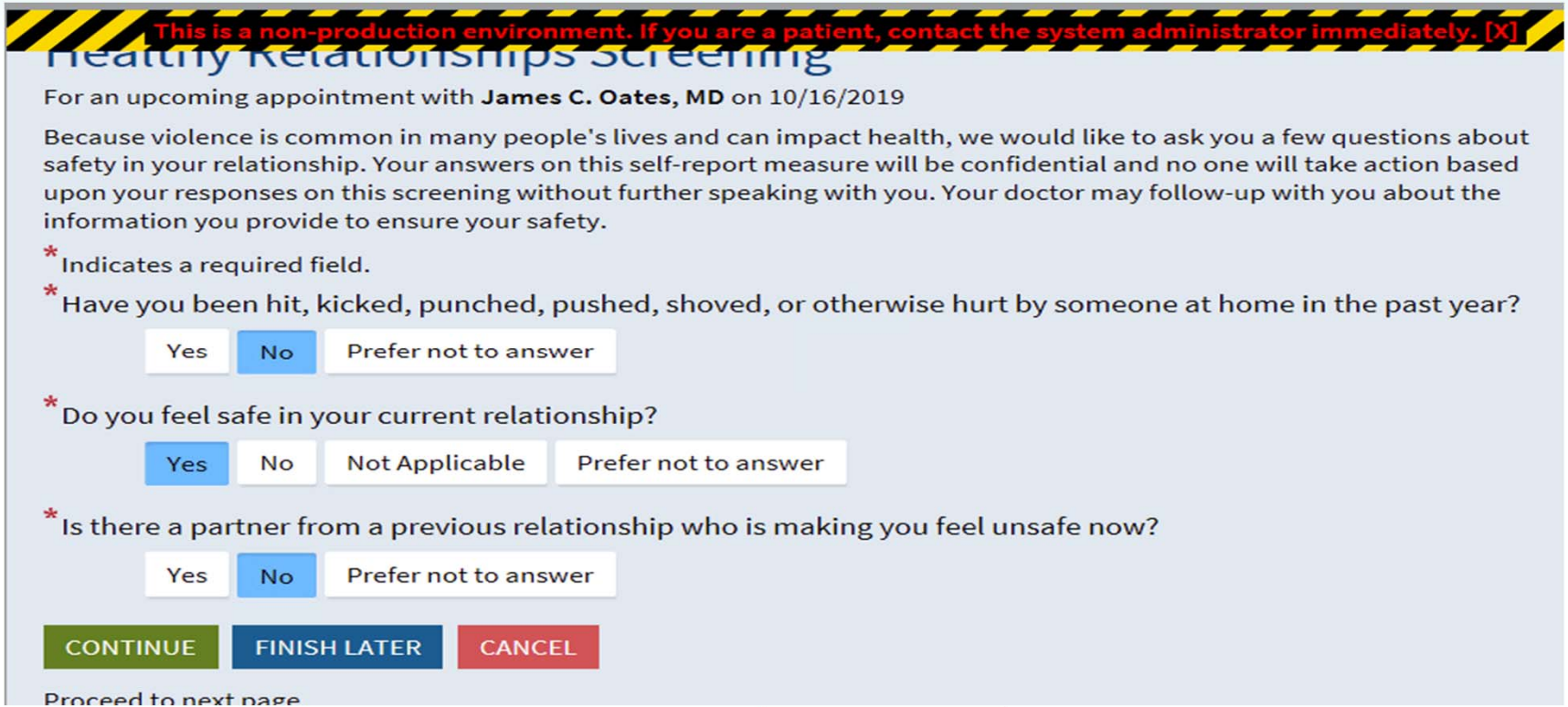
Patient Reported Outcomes (PRO):
e.g HIV/Infectious Disease Clinic PRO



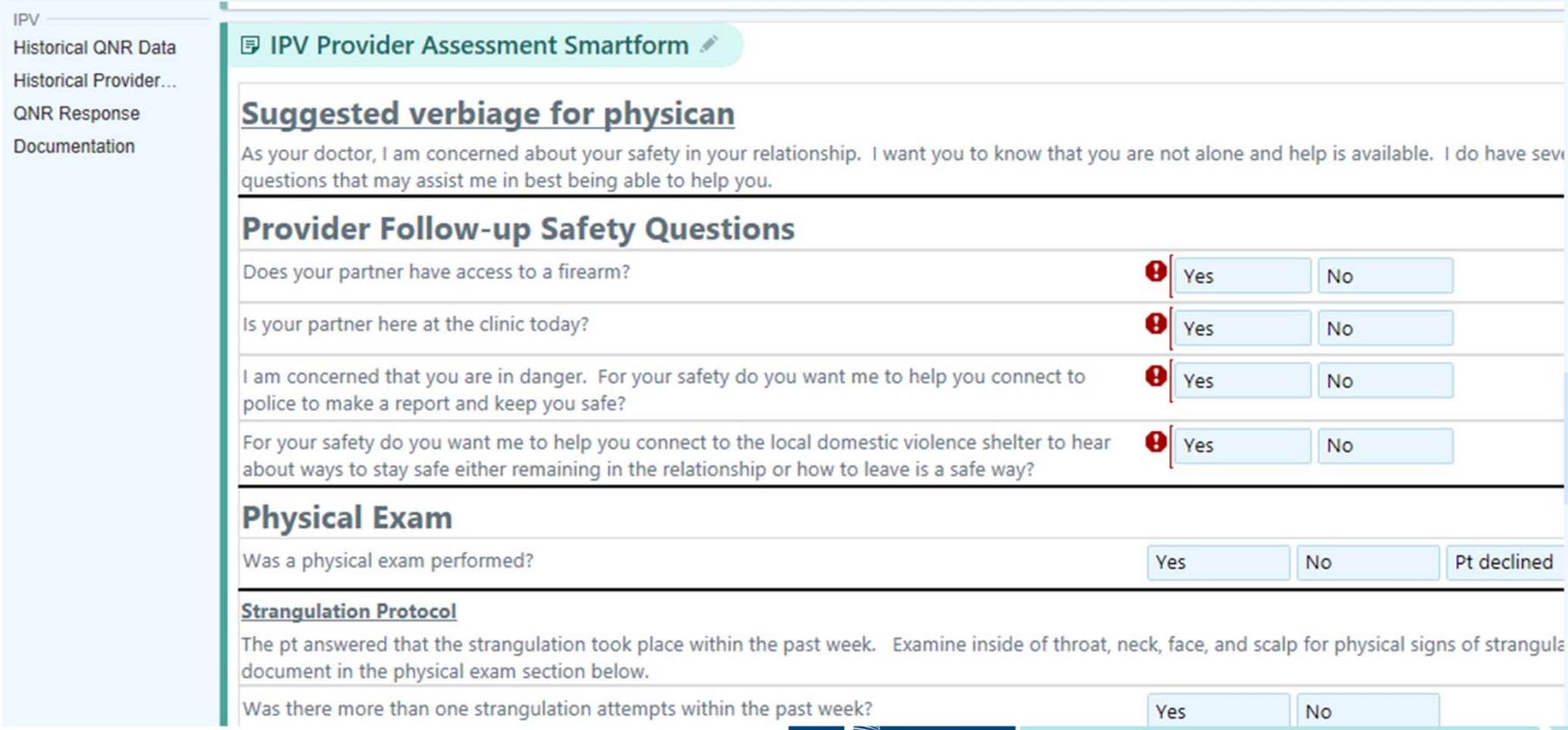


- Combination of the PHQ2, a custom medication adherence PRO, and a validated alcohol screening assessment into one streamlined PRO
- Automated send out of assessments through MyChart prior to clinical visit
- In clinic collection of PRO for those that do not use MyChart or complete the PRO ahead of time.

Patient Questionnaire: e.g. IPV Screening Tool



Provider Smart Form: e.g. IPV Screening Tool



IPV
Historical QNR Data
Historical Provider...
QNR Response
Documentation

IPV Provider Assessment Smartform

Suggested verbiage for physican

As your doctor, I am concerned about your safety in your relationship. I want you to know that you are not alone and help is available. I do have sev
questions that may assist me in best being able to help you.

Provider Follow-up Safety Questions

Does your partner have access to a firearm?	Yes	No
Is your partner here at the clinic today?	Yes	No
I am concerned that you are in danger. For your safety do you want me to help you connect to police to make a report and keep you safe?	Yes	No
For your safety do you want me to help you connect to the local domestic violence shelter to hear about ways to stay safe either remaining in the relationship or how to leave is a safe way?	Yes	No

Physical Exam

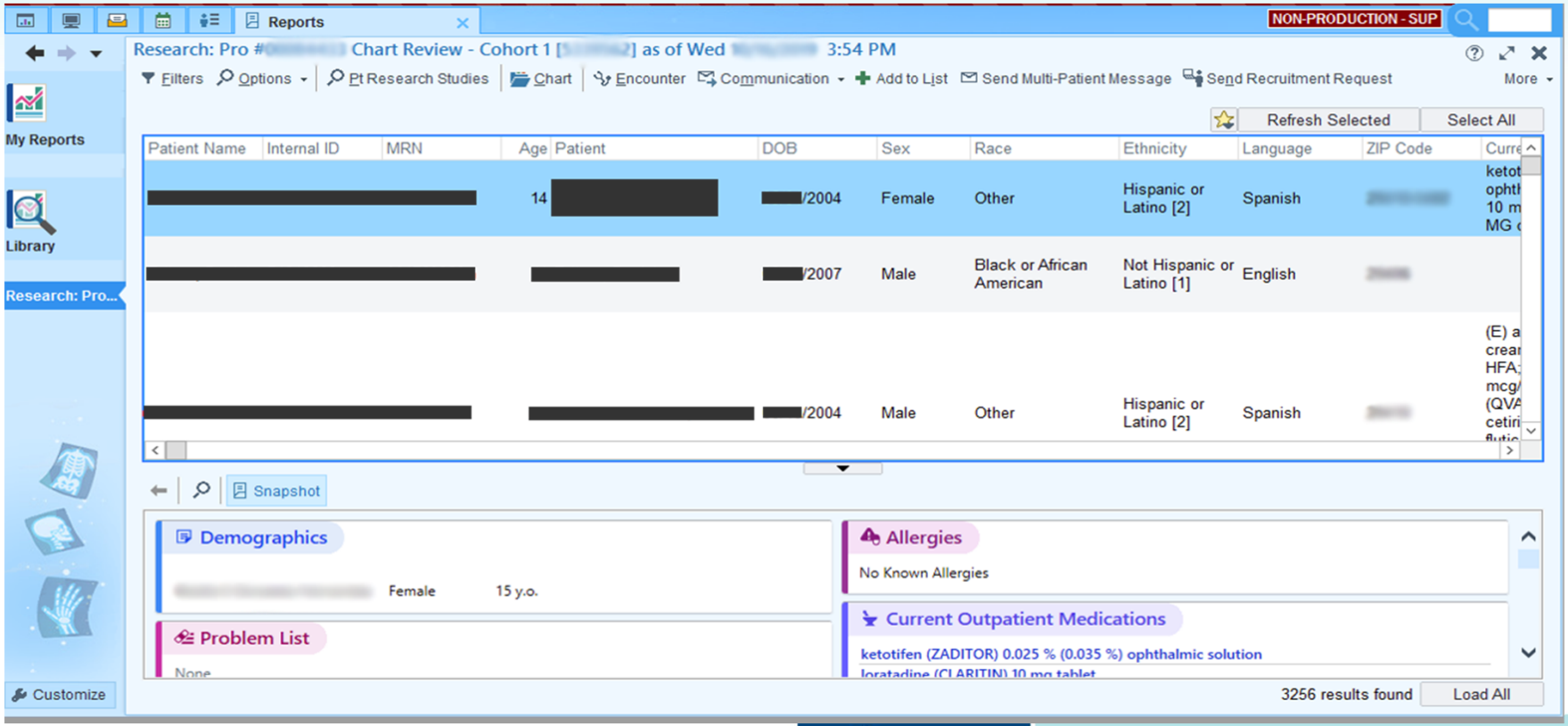
Was a physical exam performed?	Yes	No	Pt declined

Strangulation Protocol

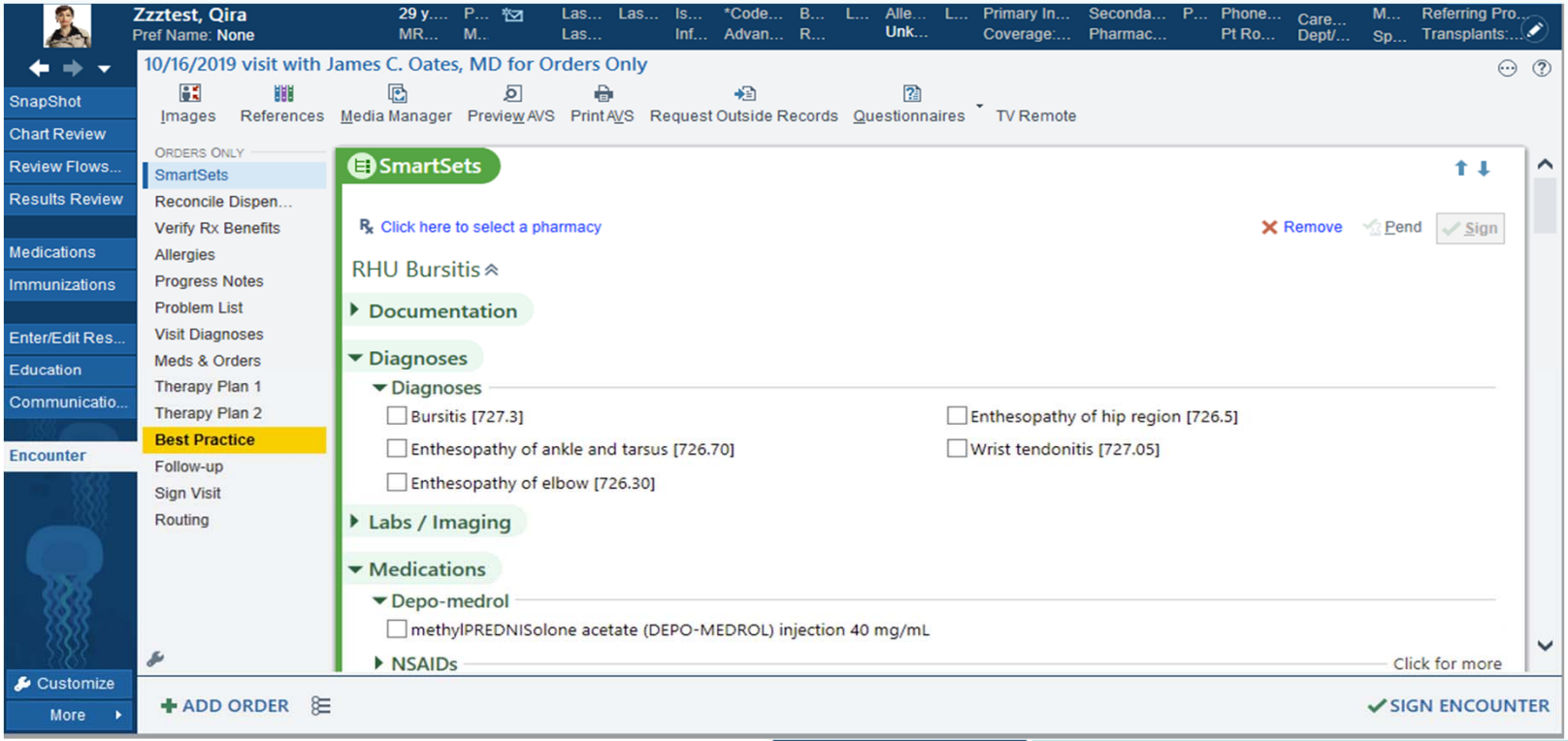
The pt answered that the strangulation took place within the past week. Examine inside of throat, neck, face, and scalp for physical signs of strangula
document in the physical exam section below.

Was there more than one strangulation attempts within the past week?	Yes	No

Recruitment Reports



Research Coordinator Order Sets



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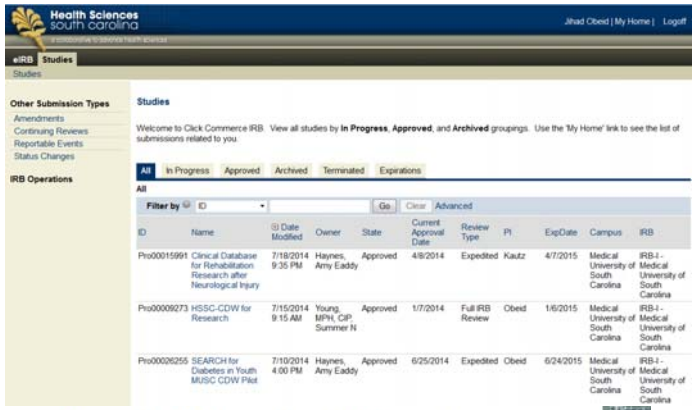
State-wide IRB Cooperative Review:

electronic IRB system (eIRB)



Journal of Biomedical Informatics

Volume 60, April 2016, Pages 58-65

IRB reliance: An informatics approach

Jihad S. Obeid [a], Randall W. Alexander [a], Stephanie M. Gentilin [a], Brigette White [a], Christine B. Turley [b], Kathleen T. Brady [a], Leslie A. Lenert [a]

Show more

https://doi.org/10.1016/j.jbi.2016.01.011

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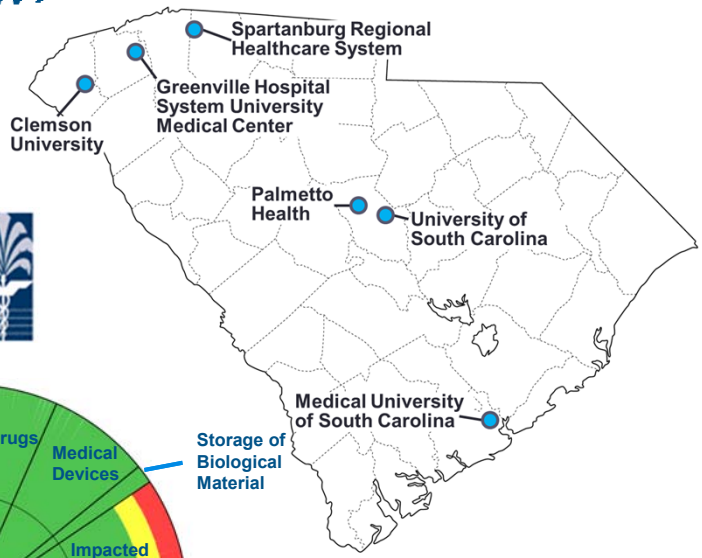
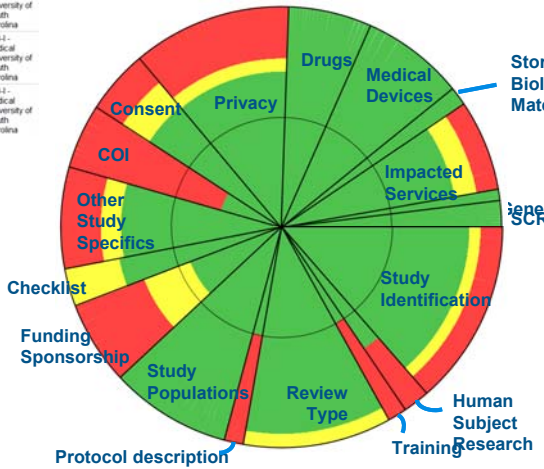


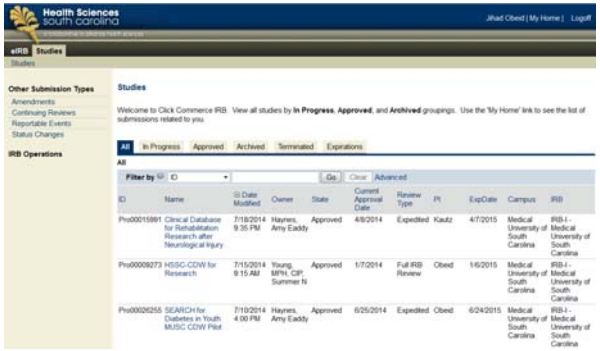
HEALTH SCIENCES SOUTH CAROLINA

Currently 5 institutions



- Pages customized for 1 institution
- Pages customized for 2 institutions
- Pages in common to all institutions

SCresearch.org



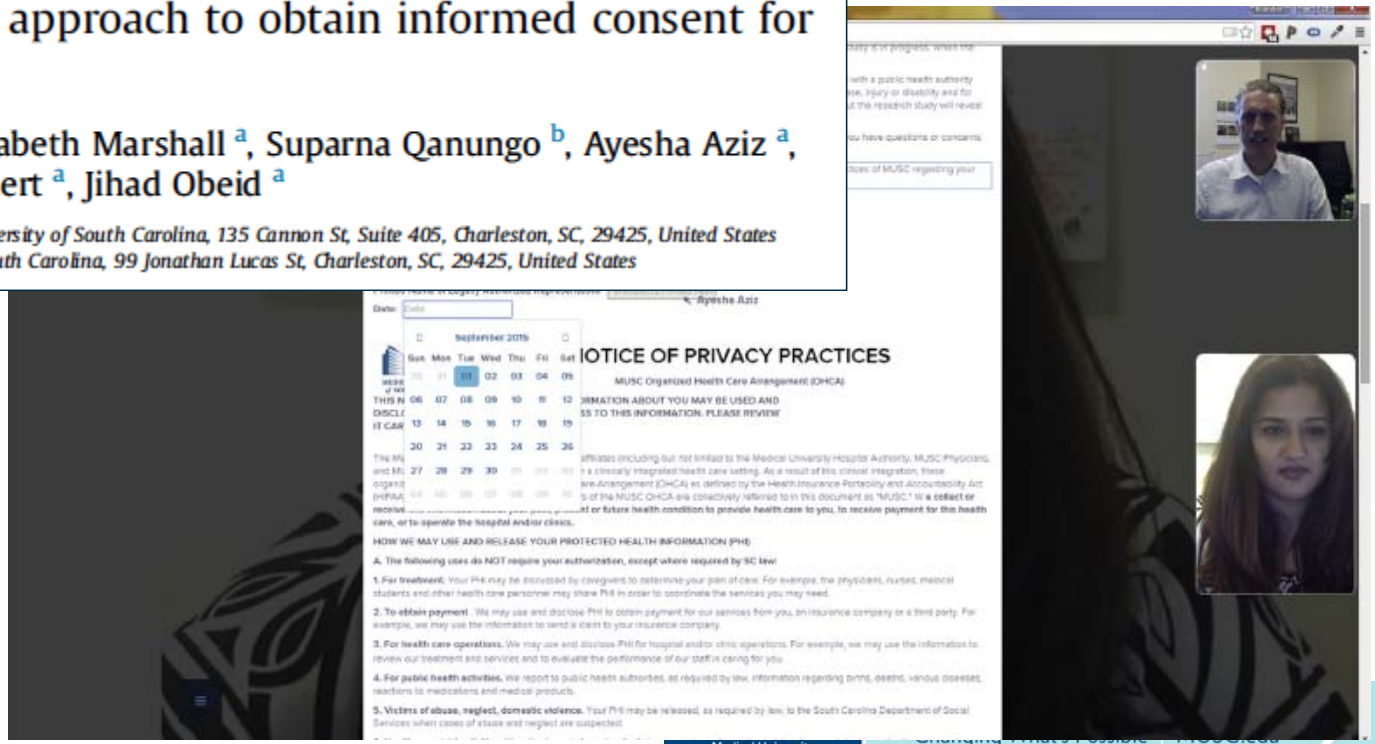
Teleconsent: e-consent over telehealth platform (doxy.me)

Contemporary Clinical Trials Communications

Teleconsent: A novel approach to obtain informed consent for research

Brandon M. Welch [a,*], Elizabeth Marshall [a], Suparna Qanungo [b], Ayesha Aziz [a], Marilyn Laken [b], Leslie Lenert [a], Jihad Obeid [a]

[a] Biomedical Informatics Center, Medical University of South Carolina, 135 Cannon St, Suite 405, Charleston, SC, 29425, United States
[b] College of Nursing, Medical University of South Carolina, 99 Jonathan Lucas St, Charleston, SC, 29425, United States



Grant number:
R21TR002088

Digital Health Solutions (DHS)

EHR & HIE Interoperability

DHS has cutting edge solutions to advance the semantic interoperability and standards-based health information technology systems allowing for critical and successful healthcare reform within digital health landscape.

Sachin Patel

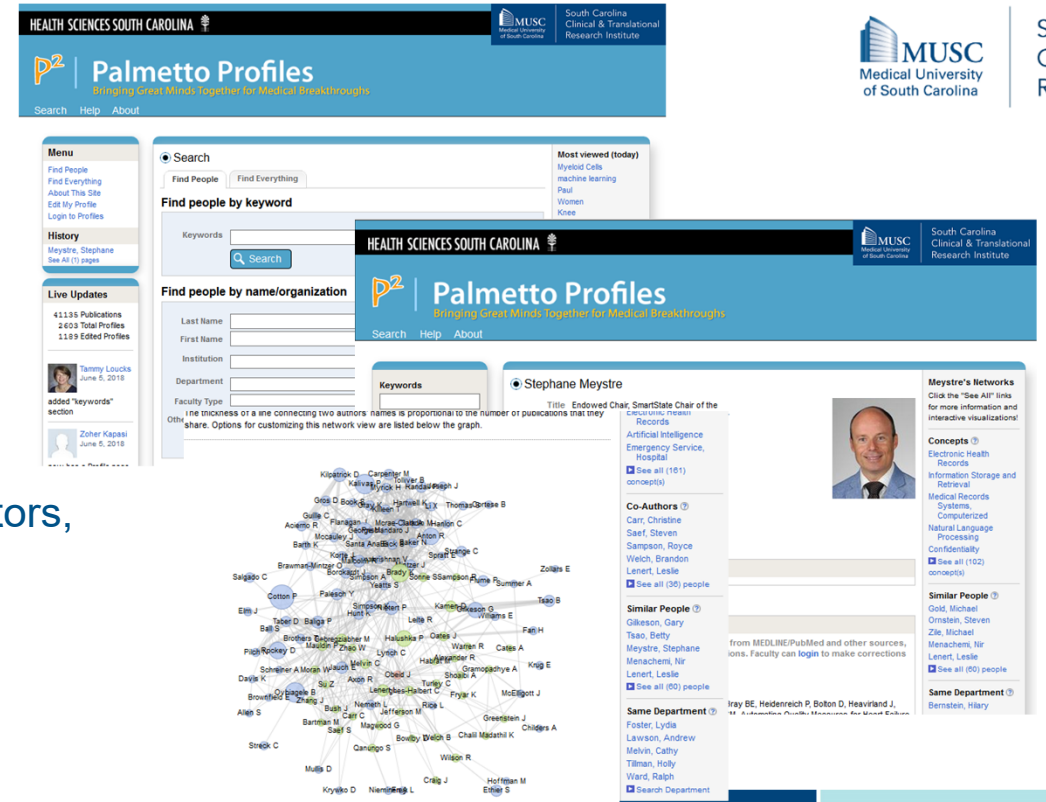
Palmetto Profiles: Research Networking System

Online CV
Automatic publications updates

+

Find experts, collaborators, mentors, reviewers etc.

Clean data for network analysis



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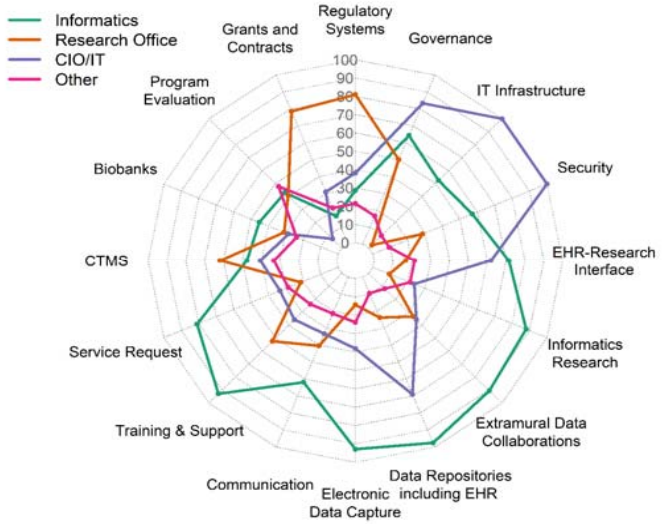
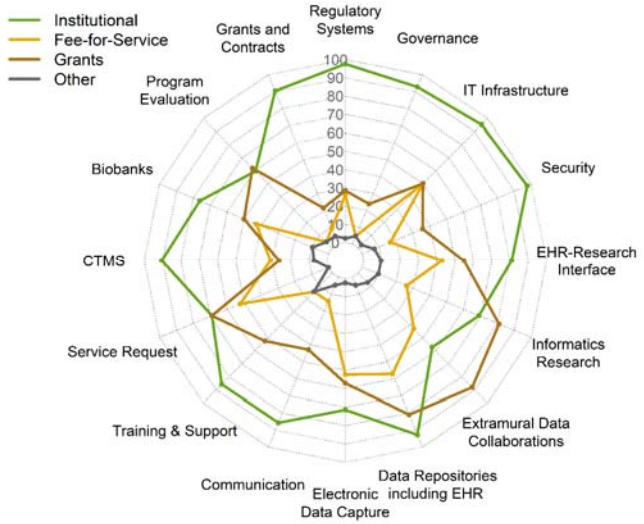
Research Network Analysis:

Impact of CTSA & Pilot Funding (Based on RNS data)

Similar Infrastructure Across the Country: CTSA Survey



a. Locus of Control



b. Sustainability Model

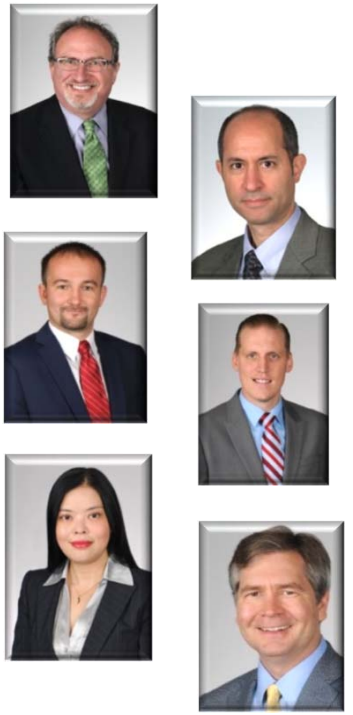
Obeid JS, Tarczy-Hornoch P, Harris PA, Barnett WK, Anderson NR, Embi PJ, Hogan WR, Bell DS, McIntosh LD, Knosp B, Tachinardi U, Cimino JJ, Wehbe FH. Sustainability considerations for clinical and translational research informatics infrastructure. *J Clin Transl Sci.* 2018 Oct; 2(5):267-275. PMID: 30828467.

Outline

- Biomedical Informatics for Translational Research
- EHR Data for Research
- Research Permissions
- Data Capture
- Epic Services
- Other Informatics Tools and Services
- Data Science Research and Education

Informatics and Data Science Research

- K07 CA211786 (Family History Data Capture)
- 3UL1 TR001450-03S2 (Multisite e-IRB)
- R21 TR002088 (Teleconsent for Remote Research)
- R18 HS025654-01A (Pragmatic EHR-based trial of IPV screening)
- R21 LM012945 (Intelligent Summarization of EHR records for IPV risk)
- R21 TR002513 (Living Biobank: Microbiome specimens)
- UL1 TR001450-04S1 (CTMS implementation)
- K12 DA031794 (Zhu, Opioid abuse identification using NLP)
- UL1 TR001450-04S2 (Cloud implementation SparcRequest)
- U01 TR002628-01A1 (Opioid Overdose Network)
- PCORI Improving Natural Language Processing Methods (NLP)
- +Several Collaborative Grants



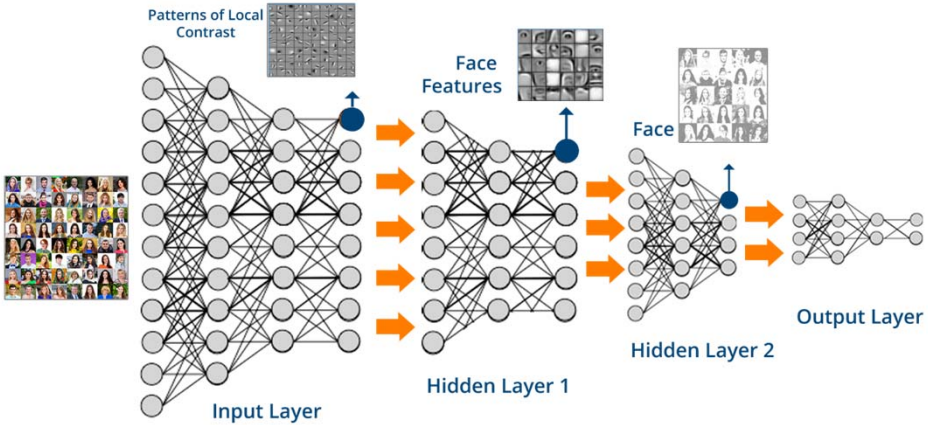
EHR Phenotyping: Machine Learning & Text Classification

Examples outside healthcare industry:

- Sentiment analysis: e.g. book reviews
- Spam detection

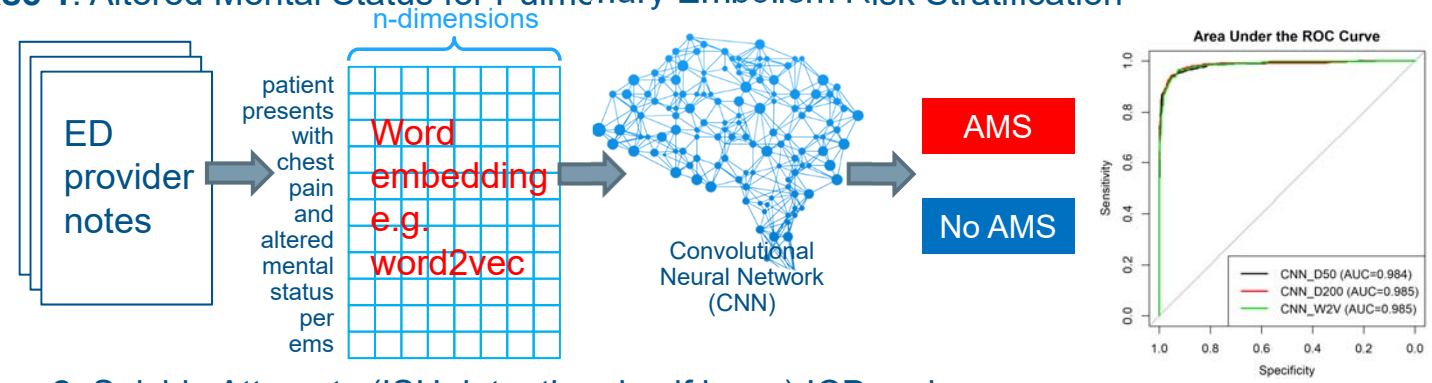
Machine learning:

- Traditional bag-of-words (BOW) models based on word frequencies
- More recently using deep learning classifiers

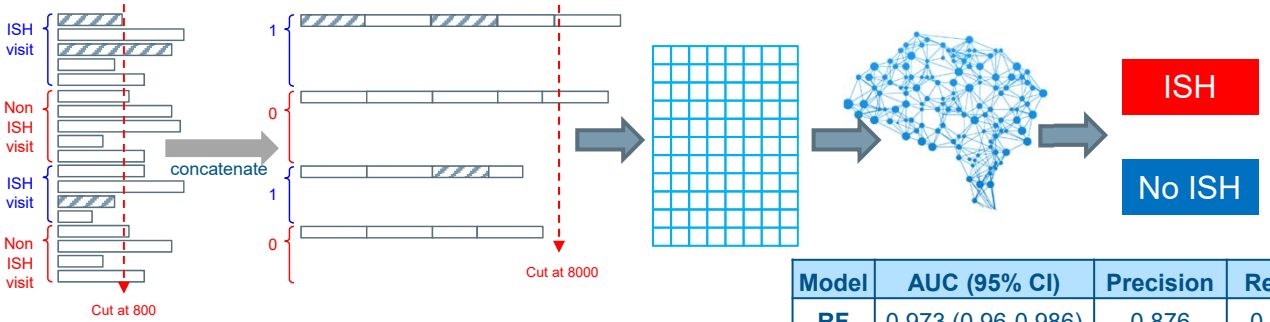


EHR Phenotyping using Deep Learning Text Classifiers

Use case 1: Altered Mental Status for Pulmonary Embolism Risk Stratification



Use case 2: Suicide Attempts (ISH=intentional self harm) ICD codes



Model	AUC (95% CI)	Precision	Recall	F1
RF	0.973 (0.96-0.986)	0.876	0.904	0.890
CNN	**0.988 (0.981-0.996)**	**0.950**	**0.916**	**0.933**

Can we predict Suicide Attempts before occurrence in EHR?

MS in Clinical Research (MSCR)

Overview

Training in clinical research for health care professionals

Learning Objectives

1. Conduct a comprehensive and systematic review of the literature
2. Formulate a well-defined clinical or translational research question
3. Select an appropriate study design to address a clinical or translational research question
4. Compute, describe, and evaluate descriptive and inferential statistics appropriate to the chosen study design
5. Apply ethical codes and professional standards for the conduct of clinical and translational research

Includes Informatics

MCR 746-01 Informatics and Data Management for Clinical Research

More at: https://gradstudies.musc.edu/programs/masters/clinical-research

PhD Program in Biomedical Data Sciences and Informatics (BDSI)

MUSC Medical University of South Carolina

CLEMSON UNIVERSITY

Joint program between MUSC and Clemson:
BMIC/DPHS at MUSC and
Departments of Public Health Science and Computer Science at Clemson

More at: https://www.cs.clemson.edu/bdsi/