The Biomedical Informatics Infrastructure for Translational Research at MUSC

Jihad S. Obeid, MD, FAMIA
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
- SCResearch.org
- Research Permissions
- eIRB
- Epic
- HSSC CDW (Statewide) & Master Patient Index
- RDW (MUSC)
- NLP and Machine Learning
- REDCap
- Research Electronic Data Capture
- SPARC Request
- CTSA Services, Budgeting, Epic Integration for Clinical Trials
- i2b2
- Statewide Clinical Trial Feasibility & Cohort Analysis
- Palmetto Profiles
- 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

Part time

Stephane Meystre, MD, PhD
Assistant Professor

Vivienne Zhu, MD, MS
Assistant Professor

Christine Carr, MD
Professor

Christopher Metts, MD
Assistant Professor

THE ONLY BIOMEDICAL INFORMATICS PROGRAM IN SC
SPARC Request: https://sparc.musc.edu/
Outline

• Biomedical Informatics for Translational Research
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• Data Science Research and Education
Legacy EDW (old data)

Includes:
- Research permissions
- Cancer Registry
- Genomics

Text Notes
(Clinic, Discharge, Radiology, etc.)

ETL

EHR
Epic+
Clarity

Research Data Warehouse (RDW)

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

Research Data Marts:
Analytics, Machine Learning, NLP, Reporting Dashboards

MUSC ontology

I2b2 Star

PCORnet CDM

TriNetX

Microbiome

MUSC Research Data Warehouse (RDW)
Governance of EHR Data for Research (IRB Approved)

Including data consults and honest broker for identified data access

Self-Service Access and Consults

- Data Use Agreement
- Researchers
- i2b2
- TriNetX
- De-identified

Brokered Access

- IRB approval
- Data Request Cmt
- Honest Broker
- Results
- Epic
- + Other data

RDW
i2b2 at MUSC: https://i2b2.musc.edu/
Collaborative Networks

PCORN
- The National Patient-Centered Clinical Research Network

STAR
- Stakeholders, Technology, and Research CRN

CTSA
- Clinical & Translational Science Awards

Networks
- National
  - ACTNetwork
  - SHRINE
  - i2b2
  - PCORnet
- Regional
  - Carolinas Collaborative, MidSouth, Southeastern SHRINE
- Statewide
  - HSSC i2b2
- MUSC
  - Local RDW, i2b2, SD, Other...
Network Capacity (SCTR)

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

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.

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

- Text Notes (Clinic, Discharge, Radiol, etc.)
- EHR
- Research permissions registry in Epic
- Cancer Registry + Other systems
- RDW
- Legacy EDW (old data)
- Mapping

I2b2 (de-identified)

Self-service access (cohort exploration)

Cancer Registry + Other systems

Biobank Preference
Contact Preference

Changing What’s Possible | MUSC.edu
Response Breakdown

Questionnaire Response Rate

- Did not respond: 68%
- Responded: 32%

Future Contact

- Yes: 73%
- Other: 27%

Biobank

- Yes: 77%
- Other: 23%

n = 79,834

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 Shoabi,1 Jim C. Oates,2,3 Melissa L. Habrat,1 Chanita Hughes-Halbert,4 and Leslie A. Lenert1

JAMIA Open, 1(2), 2018, 202–209
doi: 10.1093/jamiaopen/ooy034
Race Breakdown: across patient portal and research permissions

n = 79834 25768 18892 19713

Attrition in minorities across the process
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• **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
Consortium >3800 Members

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

Branching Logic

Drag-N-Drop Logic Builder

Displaying field choices for the following data collection instrument:

Field choices from other fields
(drag a choice below to box on right)

- `study_id = (define criteria)`
- `last_name = (define criteria)`
- `first_name = (define criteria)`
- `dob = (define criteria)`
- `sex = Female (0)`
- `sex = Male (1)`
- `address = (define criteria)`
- `phone_number = (define criteria)`
- `problems = a (1)`

Show the field ONLY if...
- ALL below are true
- ANY below are true

Drag and Drop
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 in this study, contact the Research Manager, Office of Research Compliance, University of South Carolina, 414D, Columbia, SC 29208, phone: phone number.

Consent:
By signing this form, I confirm that I have read and understood the consent form, have been given the opportunity to ask questions or request more information, understand that participation is voluntary and that I have the opportunity to withdraw at any time.
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Living Biobank: Specimen/data request submission
BMIC Gateway Streamlines Two-way Integration with Epic

- **Backend**
  - JSON, XML
  - HL7, JSON, XML, PUSH into External Database, Push into Epic

- **Microservice 1**
  - FHIR Standard API

- **Microservice 2**
  - Real-Time Epic FHIR Resource Rest-Hook based Subscription, Notification

- **Microservice 3**
  - CDS Service Provider (Value-Driven Care Support based on CDS Hooks)

- **Microservice 4**
  - API Bridges between FHIR and Redcap, OnCore, and SPARC Request

- **BMIC RESTful API Portal**
  - API Keys Registration
  - Documents
  - Logs
  - Monitors
  - Manage security and routing between multiple services.
  - Custom Resources
  - Security & Access Control
  - Subscriptions
  - CDS Hooks

- **BMIC REST API Gateway**

- **Integrating Your Applications into Epic Hyperspace**
  - Mobile App
  - Web App
  - bulk data exchange

- **FHIR Server**
- **Fhirbase**
- **Epic Clarity**
- **REDCap**
- **SPARC**

- **Security & Access Control**
  - Subscriptions
  - CDS Hooks

- **Custom Resources**

- **API Keys Registration**

- **Documents**

- **Logs**

- **Monitors**

- **Manage security and routing between multiple services.**

- **Custom Resources**
  - Security & Access Control
  - Subscriptions
  - CDS Hooks
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

For an upcoming appointment with James C. Oates, MD on 10/16/2019

Because violence is common in many people's lives and can impact health, we would like to ask you a few questions about safety in your relationship. Your answers on this self-report measure will be confidential and no one will take action based upon your responses on this screening without further speaking with you. Your doctor may follow-up with you about the information you provide to ensure your safety.

* Indicates a required field.

* Have you been hit, kicked, punched, pushed, shoved, or otherwise hurt by someone at home in the past year?
  - Yes
  - No
  - Prefer not to answer

* Do you feel safe in your current relationship?
  - Yes
  - No
  - Not Applicable
  - Prefer not to answer

* Is there a partner from a previous relationship who is making you feel unsafe now?
  - Yes
  - No
  - Prefer not to answer

CONTINUE  FINISH LATER  CANCEL

Proceed to next page.
**Provider Follow-up Safety Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your partner have access to a firearm?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Is your partner here at the clinic today?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>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?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>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?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**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 strangulation and document in the physical exam section below.

- Was there more than one strangulation attempt within the past week?
  - Yes
  - No
## Recruitment Reports

![Screen capture of a recruitment report interface displaying patient information]

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Internal ID</th>
<th>MRN</th>
<th>Age</th>
<th>DOB</th>
<th>Sex</th>
<th>Race</th>
<th>Ethnicity</th>
<th>Language</th>
<th>ZIP Code</th>
<th>Current Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>14</td>
<td>2004</td>
<td>Female</td>
<td>Other</td>
<td>Hispanic or Latino [2]</td>
<td>Spanish</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>2007</td>
<td></td>
<td>Male</td>
<td>Black or African American</td>
<td>Not Hispanic or Latino [1]</td>
<td>English</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

- **Current Outpatient Medications**
  - ketotifen (ZADITOR) 0.023 % (0.035 %) ophthalmic solution
  - loratadine (CLARTIN) 10 mg tablet

- **Allergies**: None

- **Problem List**: None

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**MUSC Medical University of South Carolina**

Changing What’s Possible  MUSC.edu
Research Coordinator Order Sets

10/16/2019 visit with James C. Oates, MD for Orders Only

SmartSets

Click here to select a pharmacy

RHU Bursitis

Documentation

Diagnoses

- Enthesopathy of hip region [726.5]
- Wrist tendonitis [726.05]

Diagnoses

- Bursitis [727.3]
- Enthesopathy of ankle and tarsus [726.70]
- Enthesopathy of elbow [726.30]

Labs / Imaging

Medications

Depo-medrol

methylPREDnisolone acetate (DEPO-MEDROL) injection 40 mg/mL

NSAIDs

+ ADD ORDER ✔ SIGN ENCOUNTER

Changing What’s Possible   MUSC.edu
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State-wide IRB Cooperative Review: electronic IRB system (eIRB)

Currently 5 institutions

Pages customized for 1 institution

Pages customized for 2 institutions

Pages in common to all institutions

IRB reliance: An informatics approach

Jihad S. Olweid 1,2,3, Randell W. Alexander 4, Stephanie M. Gentiliun 5, Brigette White 4, Christine B. Turley 4, Kathleen T. Brady 5, Leslie A. Lenert 4

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

Under an Elsevier user license
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
Research Network Analysis:
Impact of CTSA & Pilot Funding
(Based on RNS data)
Similar Infrastructure Across the Country: CTSA Survey

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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

ED provider notes → patient presents with chest pain and altered mental status per ems → Word embedding e.g. word2vec

Convolutional Neural Network (CNN) → AMS

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

ISH visit → concatenate → ISH

Can we predict Suicide Attempts before occurrence in EHR?

<table>
<thead>
<tr>
<th>Model</th>
<th>AUC (95% CI)</th>
<th>Precision</th>
<th>Recall</th>
<th>F1</th>
</tr>
</thead>
<tbody>
<tr>
<td>RF</td>
<td>0.973 (0.96-0.986)</td>
<td>0.876</td>
<td>0.904</td>
<td>0.890</td>
</tr>
<tr>
<td>CNN</td>
<td>0.988 (0.981-0.996)</td>
<td>0.950</td>
<td>0.916</td>
<td>0.933</td>
</tr>
</tbody>
</table>
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)

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/