Information Technology Resources for the Investigator

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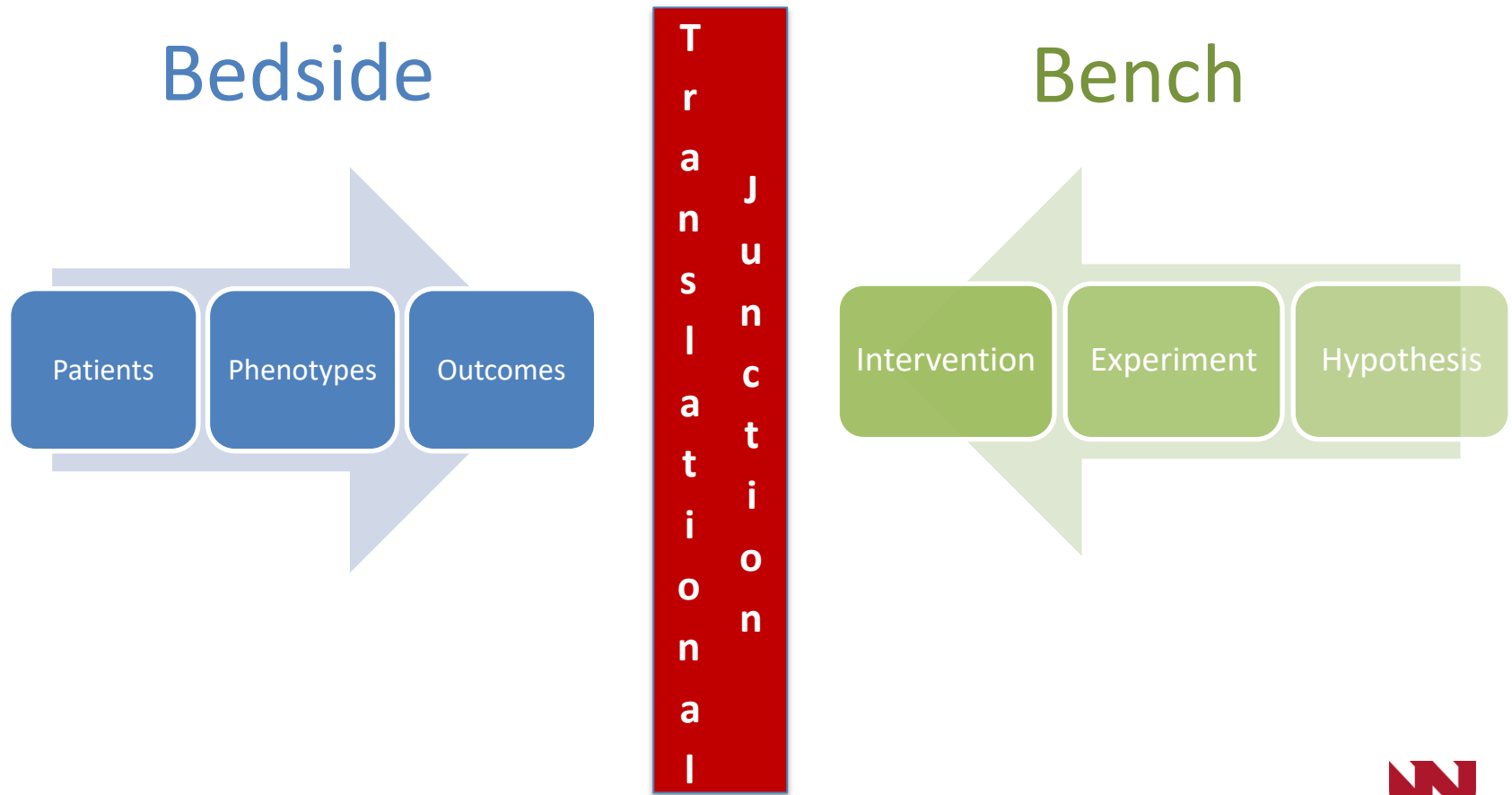**May 14, 2020**

University of Nebraska Medical Center

Nebraska Medicine

Primary Data – Bridge the Gap

Bedside

Bench

| Patients | Phenotypes | Outcomes |

Translational Junctional

| Intervention | Experiment | Hypothesis |

Data Lake?

Not all data is clean or "good"

Tools to get good data

Characterized (annotated) data is cleaner data

Dirty data needs to be cleaned

Resources

- Datasets

- Biorepositories

- Software tools and information technology support

- Consultation

Data sets

- Electronic Health Record Data
  - CRANE
  - Slicer-dicer
  - EHR Access Core (Dr. Guda)

Electronic Health Record Data

- Clinical Research Analytics Environment (CRANE)
    - Based on PCORnet model
    - Highly annotated EHR data (subset)
    - De-identified and identified versions
    - Within 90-days of current
    - Contact: Dr. James C. McClay

- Slicer-dicer
    - EPIC® embedded tool
    - Fast, ad hoc
    - Access to patient data in your chain of care
    - Data NOT annotated, follows EPIC data model and UNMC build
    - Must understand our EPIC build

Biorepositories

- NE biobank (Dr. Guda)
  - Blood
  - De-identified
  - Consented

- Pathology managed (Dr. Ben Swanson; bjswanso@unmc.edu)
  - Paraffin-embedded
    - Excess tissue – consented
    - Frozen tissue – consented (limited quantities)

- Specialty-specific
  - iCares2 – Oncology. Consented, multiple tissue types.
  - Rheumatology (RAIN).
  - Pancreas Rapid Autopsy.

Software tools and information technology support

Research IT Office (RITO)
(https://www.unmc.edu/vcr/rito/index.html)

IT department dedicated to meeting needs of the researcher

Services:
- REDCap
- Server provisioning and management
- Data storage
- Research software applications (e.g., MatLab)
- Access to supercomputing resources (Holland Computer Center)

REDCap (Research Electronic Data Capture)

- Secure web application for collecting data
    - Survey Data (email capable)
    - Customizable
    - Data stored in straight forward data structure and accessible by investigator
    - Two "flavors"
- Research, non-clinical – RITO managed
    - Not stored as part of clinical record
    - NOT 21 CFR part 11 compliant (not to be used for FDA trials)
    - Free for one year, then annual fee
- EPIC-bound, incorporated in clinical workflow – ITS managed
    - Data stored in EPIC data structures
    - Data part of clinical record (e.g., new or adjusted neurologic assessment instrument)

Data Storage

- Paramount to understand what can be stored where

- ANY data containing protected health information (PHI) MUST be stored in a UNMC approved mode
    - On UNMC or NM managed device (encrypted)
    - UNMC Box.com
        - Linked to your UNMC account
        - Co-Managed by ITS
    - UNMC One-drive
    - UNMC managed, centralized storage (data center)

- USBs and external storage devices will be encrypted by UNMC

Data Privacy/PHI

Nebraska Medicine – Data privacy
Nebraska Medicine data sharing and/or release subject to Privacy Officer Approval

PHI – HIPAA
1. Names;
2. All geographical subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code, if according to the current publicly available data from the Bureau of the Census: (1) The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and (2) The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people is changed to 000.
3. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
4. Phone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social Security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voice prints;
17. Full face photographic images and any comparable images;
18. Any other unique identifying number, characteristic, or code (note this does not mean the unique code assigned by the investigator to code the data)

Where to start?

- All things technology have nuances when deployed in our environment

- Many of the nuances are not on the top of our minds as PI's
    - Security
    - Data management
    - Software licensing
    - The overall process of navigating UNMC/NM

- Call and ask for input…really even if only for peace of mind

Questions

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