Digital health research software at the NHS research interface in Leicester and beyond

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1. Research at UHL / UoL
2. BRISSKit: Biomedical Research Software as a Service
3. Use cases, Open Source code and documentation

http://www.brisskit.le.ac.uk
@BRISSKit
Research at UHL with UoL

University Hospital of Leicester NHS Trust (an incomplete picture)

- 3 NIHR Biomedical Research Units (total funding > £19m)
- Experimental Cancer Medicine Research Centre
- Host 3 NIHR research networks:
  - South East Midlands Diabetes Network
  - Trent Stroke Research Network
  - Leicestershire, Northamptonshire and Rutland Comprehensive Local Research Network
- Host an NIHR Collaboration in Leadership for Applied Health Research and Care (CLAHRC)
- Strong relationship with University of Leicester, including the Clinical Trials Unit, but developing links with several other Universities in the new East Midlands Academic Health Science Network; 100k Genomes
What is BRISSKit?

SEE 2 MINUTE ANIMATED EXPLAINER!

https://www.brisskit.le.ac.uk/node/61
BRISSKit CiviCRM: patient cohort management

- Manages studies: enables end-to-end contact management for volunteers and research participants
- Track approaches, contact, responses, recruitment, exclusions
- In use for 22k recruits in 14 studies (Cardiovascular); new development for NIHR Lifestyle BRU, 100k Genomes
BRISSKit OpenSpecimen: sample management

- Holds data on primary, derived and aliquot specimen, including linear and 2d barcodes
- Storage inventory, order tracking e.g. 100,000+ samples NIHR UHL Cardiovascular BRU in 5+ yrs; Cancer Biobank - next slide

http://www.brisskit.le.ac.uk
Leicester Cancer Research Biobank

Cancer research is currently in an era in which thousands of genes, RNA molecules and proteins can be analysed in a single experiment, meaning that large numbers of potential molecular markers for cancer are being identified. To validate and translate these biomarkers large series of tissue and other biosamples are required.

The Cancer Research UK Leicester Centre and University Cancer Theme which oversees the cancer research strategy at Leicester, recognises that a joined up approach to cancer sample collection and storage is needed. The University of Leicester Cancer Research Biobank is intended to meet this need and to facilitate high quality research.

The Biobank will support projects from all sections of the cancer research community within Leicester, while remaining open to provision of tissues to organisations outside Leicester.

Researchers from academic, charitable and commercial organisations will be able to apply for access to banked tissue samples.

The Leicester Cancer Research Biobank is a member of, and accredited by, the National Cancer Research Institute - Confederation of Cancer Biobanks.

The Leicester Cancer Research Biobank also has full ethical approval, bestowed by NRES Committee East Midlands Derby (Ref: 13/EM/0196; IRAS 103613) and is operated under Human Tissue Act Licence 12384.

• Open Specimen - Sample tracking for LCCB, Tracer X, Mesobank

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BRISSKit RedCap: survey management

Web-based, secure questionnaire data entry by research or nursing staff

E.g. used for all patient recruits in NIHR UHL Respiratory Biomedical Research Unit - mobile computing on wards and outpatient clinic

- Exceed Study (Tobin)

http://www.brisskit.le.ac.uk
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- Redcap - Lung Adenocarcinoma - 994 cases (imported demographics from ilab and Apex, Cancer registry data); Mesothelioma - 50 cases and growing; T-non-Hodgkin's lymphoma (NHL) - 3 sites incl Bham, Nham
Example BRISSkit Implementation

NHS Host Institution
- Patient Master Index
- Clinical data
- Imaging and other systems
- NHS staff and researchers

Researchers
- National or international collaboration
- Other local researchers
- Biomedical Research Group

Relationship management CiviCRM

Sample tracking caTissue

Electronic data capture OBiBa Onyx

Other components (e.g. REDcap)

Data warehousing i2b2

Data querying i2b2

Identifiable data

Anonymised data

Access Control

http://www.briisskit.le.ac.uk
BRISSKit i2b2: data warehousing & querying

Data from multiple data sources combined into multiple ontologies for flexible and sophisticated searching, cohort discovery and research
Research: the semantic bridge

Survey data

Records participant consent, questionnaire data and primary specimen IDs

Bio-ontology!

- **Classes**
  - BrissKitQuestionnaire
  - RiskFactorAlcohol
  - RiskFactorCigars
  - RiskFactorCigs
  - RiskFactorDietExercise
  - RiskFactorFamilyHistory
  - RiskFactorOtherTobacco
  - RiskFactorSocioeconomic
  - RiskFactorTobacco

- **HPO**
  - All
    - Phenotypic abnormality
      - Abnormality of the cardiovascular system
      - Abnormality of the hematopoietic system
  - Diseases of the circulatory system
  - Diseases of the skin and subcutaneous tissue
  - Factors influencing health status and contact with health services
  - Persons encountering health services in other circumstances

- **ICD10**

- **LOINC**
  - LOINCCLASSTYPES
    - Clinical Class
      - Functional status (e.g., Glasgow)
      - Gastrointestinal endoscopy
      - Medical Devices

- **SNOMED-CT**
  - Clinical finding
  - Functional finding
  - Hepatorrhaphy
  - Observable entity
  - Organism
  - Social and personal history finding
  - Substance
  - Tobacco smoking behavior - finding
  - Tobacco use and exposure - finding

I2b2 data query

Support selection and querying
BRISSKit Information Governance & Security Management Work Stream

1. **Information Governance Toolkit** - analysis of Department of Health (DoH/NHS) IGT requirements vs. BRISSKit organisation/project and services/tools
   a) Hosted Secondary Use Team/project (**Hosted IGT**)
   b) Acute Trust (**Acute Trust IGT**)

2. **IG Training Tool** (NHS – University is registered)
   – **UoL College of Medical Biological & Psychological Sciences wide registration**

3. **Pseudonymisation** requirements

4. **Data Management Plan**


6. Other **NHS Standards/Requirements**:
   - Care Records Guarantee
   - NHS Constitution
   - NHS Records Management
   - Patient Safety DSCN 14/2009, 18/2009

*NB – Partnerships available via Aimes, Skyscape for secure IGT compliant DB hosting*
Code Release

- **code base** will now be made freely available to the community via suitable repositories
  - Complete the open source release of all work done so far: 95 repositories need to be released in total
  - Ensure all licences are correct
  - Fully documented

- set of **documentation** and explanatory materials to support further take up and use
  - puppet management, maven build manager and provisioning of virtual machines
  - integrations between the applications

- final release end Mar 2016
BRISSKit endorsed by NHS England!

Apperta Foundation Challenge

Our challenge is now closed, join us at EHI Live in November 3rd/4th where the results have been announced.

http://www.ehilive.co.uk/

The Apperta Foundation for Health and Care announced a Code4Health challenge at the Health & Care Expo 2-3 September in Manchester, challenging interested parties to submit ideas which utilises existing or new open source resources to provide a solution they feel is required across health and social care.

Submissions were assessed, all are now shortlisted and are asked to create a Code4Health Community (if one doesn’t exist) and will be provided with guidance and resources via the Apperta Foundation to create and develop the solutions further.

Apperta Foundation Challenge Submissions

- **NET**
  - Bolton CAMHS
  - Mobile Safety Plan for Children and Young People with Mental Health Difficulties

- **Care Home Dementia Diagnosis**
  - Yorkshire & The Humber Strategic Clinical Network
  - Making a diagnosis of established dementia in a care home setting

- **“What’s the Plan?”**
  - “What’s the Plan?” Code4Health Community
  - The Open Care Plan

- **National Cataract Audit Platform**
  - Moorfields Eye Hospital/Cardiff University
  - Making a diagnosis of established dementia in a care home setting

- **Appetite**
  - Guys & St Thomas NHS Trust
  - Web based personalised dietary tool for patients with cancer

- **Pathways**
  - Guys & St Thomas NHS Trust
  - Web based personalised information delivery

- **BRISSKIT**
  - Integrating specimen data for analytics using open source tools

- **Safety in Your Pocket**
  - Bolton CAMHS
  - Mobile Mental Health application straight out of NHS Hack Day Manchester

- **Electronic Discharge Summaries**
  - HSCIC
  - Electronic Discharge Summaries from Acute to Primary Care
Leicester Cardiovascular Biomedical Research Unit

LCBRU Informatics Platform

A suite of established open source tools, applied to the specific context of the LCBRU's developing research agenda. Aiming to become a common platform for accelerating and enabling research.

- i2b2 – cohort discovery and phenotypic data queries
- CaTissue – biological specimen management and inventory
- ObiBa Onyx and REDCap – Questionnaire building and data capture
- CiviCRM – participant relationship management and study monitoring

With some custom implementations and data pipelines.

Future challenges: novel data types (quantitative proteomics, signal processing, etc), text processing, extended integration with clinical systems, closing the feedback loop.
“promote the development of new and effective therapies for the treatment of severe asthma and chronic obstructive pulmonary disease (COPD)”

Informatics Strategy

- Room booking (MRBS)
- Participant management – CiviCRM
- Tissue management – CaTissue Plus / OpenSpecimen
- Research project data collection – REDCap
- Data mining – i2b2/tranSMART
- Non-specific support -> e.g. data processing
- Develop projects and additional opportunities with external groups
BRISSKit highlighted collaborations

- University of Bristol / ALSPAC: PI Paul Burton
  - ALSPAC Birth Cohort Studies
  - DataShield: simultaneous remote, secure access to multiple large international cohorts
  - Environmental DataShield
  - SAIL-Farr secure NHS data hosting (Swansea)
Scoping potential of data fusion with British Geological Survey

1. KNOWLEDGE BASE: AEROSOL SOURCES, CHEMISTRY, TRANSPORT AND MEASUREMENT
2. MARKET AND SYSTEMS FEASIBILITY: INTEGRATION OF NEW TECHNOLOGY AND DATA STREAMS
3. STAKEHOLDER NEED: MANAGING HEALTH IMPACT AROUND PERSONAL EXPOSURE

WHAT KIND OF SYSTEM COULD LINK STATE-OF-THE-ART PARTICULATES DATA WITH STATE-OF-THE-ART HEALTH DATA?

Collaboration with Dr Josh Vande Hey, NERC Knowledge Exchange Research Fellow (UoL Physics & Astronomy) using BRISSKit + Bristol D2K
eHealth Leicester 2015
three days of eHealth and research meetings and workshops

Day 1  5th October 2015
Latest eHealth Opportunities: UK and International Perspectives
Sessions will focus on exploiting national, local, primary care and hospital derived data for clinical research, as well as software to enable research, and the ethical and governance framework in which we operate.

Day 2  6th October 2015
The 2015 i2b2 European Academic User Group meeting
Featuring sessions on the use of i2b2 to collate and aggregate data from clinical, genomic, imaging and other domains, both for single institution and collaborative projects.

Day 3  7th October 2015
Environmental Health Informatics Workshop and BRISSKit Hackday
A NERC funded informatics workshop on environmental health and technically-focussed 'hackday' hosted by Leicester’s BRISSKit project. We will explore problems of data acquisition, analysis or integration, using open source tools with an i2b2 focus.

http://ehealth2015.i4health.eu/
100k Genomes Use Case

- University Hospitals Leicester NHS Trust in support of Genomics England, East of England GMC
  - led by Cambridge and including Notts Trusts
  - Develop, integrate, host and support (at UHL) local instances of
    - CiviCRM patient cohort management
    - OpenClinica TBC (+ integration to BRISSKit stack)
    - Developing alongside Camb, Nott where possible
      - Phenotips?
      - Achiever?
BRISSKit USPs

- *Integrated* support for core research processes
- Well-established mature open source applications as used in e.g. Cardiovascular, Respiratory, Cancer: fully UK customised
- A cloud based platform for seamless management and integration between applications
- BRISSKit RESTful APIs allow integration with existing clinical systems
- *Easy set up, use and administration through browser (including on mobile devices)*
- Capability of being *hosted in any compliant data centre provider*:
  - Aimes, Skyscape, UHL NHS Trust, SAIL (Farr) - IGT compliant
  - UoL, Azure for Research, AWS - development, demo, anon
Contact Details

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https://www2.le.ac.uk/departments/health-sciences/research/gen-epi/staff-pages/jat26

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