

# *Research IT, Data Services & Support Model at BC Children's Hospital*

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# Agenda

- › About us
- › Impact – Research Project
- › Ecosystem
- › Principles & Approach
- › Data platforms
- › Support Model
- › Challenges
- › Questions

# In BC and Beyond

We bridge research and care to transform child health provincially, nationally and internationally.



THE UNIVERSITY  
OF BRITISH COLUMBIA

BC   
**Children's  
Hospital**<sup>TM</sup>  
Research Institute



**Provincial Health  
Services Authority**  
Province-wide solutions.  
Better health.

# People

- › We are a multidisciplinary team with expertise in:
  - › Data Management
    - › Effective collection, storage, preservation and reuse of data.
  - › Technology and Infrastructure
    - › Digital Infrastructure that is secure and supports diverse research activities.
  - › Programming and Development
    - › Building and integrating data platforms and systems.
  - › Clinical research Informatics
    - › Creating and developing data standardization and structured data approach.



# Research Project – Heartsmap

Dr. Quynh Doan, UBC, Pediatric Emergency

## Meeting Pediatric Mental Health needs in the Emergency Department

- › 1.2 Million Canadian children and youth are affected by mental illness
- › Emergency departments have increasingly become a gateway for access to specialized mental health services
- › Emergency physicians lack appropriate training for mental health assessments
- › Resulting in negative patient experience and sometimes unnecessary cost to health system
- › Development of HEARTSMAP psychosocial assessment tool
- › Implemented at ED's across BC in 5 health authorities, 657 cases assessed
- › Empowering ED physicians, improving patient experience and efficient use of mental health resources
- › Phase 2: MyHeartsmap (self assessment) Phase 3: Openheartsmap (released for world wide use)



# HEARTSMAP TOOL

HEARTSMAP  
HEARTSMAP PSYCHOSOCIAL ASSESSMENT AND DECISION-MAKING SUPPORT TOOL

Click on the following section title or letter to navigate back to this section

DemographicsHEARTSSMAPClinician Decision

## HOME

Sample Questions

Is there difficulty or fighting at home between family members?

How do you get along with [guardian/parents/family]?

How do you feel about your home environment?

Assessment Notes (DO NOT ENTER PERSONAL IDENTIFIERS) \*

Test

If not applicable, please type N/A

### Score \*

No Concerns	Mild Concerns	Moderate Concerns	Major Concerns
0	1	2	3
	Supportive of youth's difficulties but some conflicts.	Unsupportive (parents at risk for burn out). Frequent conflicts.	Dysfunctional (parental burn out). Homelessness. Major conflicts.

Resources: \*

Ⓢ Social Supports or family counseling services involved (resource requested and services initiated)

Ⓢ Social Supports or family counseling services neither requested nor initiated

PREVIOUSNEXTBACK TO LAST PAGE

### Score Summary

Home	Education and Activities	Alcohol and Drugs	Relationships and Bullying	Thoughts and Anxiety	Safety	Sexual Health	Mood	Abuse	Professionals and resources
1	2	2	2	2	2	2	3	2	3
Mild Concerns	Moderate Concerns	Moderate Concerns	Moderate Concerns	Moderate Concerns	Moderate Concerns	Moderate Concerns	Major Concerns	Mild Concerns / Moderate concerns	Major Concerns
SOCIAL Total = 5 / 9 Addressed = 3 / 3		FUNCTION Total = 6 / 9 Addressed = 3 / 3		YOUTH HEALTH Total = 6 / 9 Addressed = 2 / 3		PSYCHIATRY Total = 7 / 9 Addressed = 3 / 3		ABUSE Total = 2 / 3 Addressed = 1 / 1	

### Recommendations

- SOCIAL**
- Refer to social worker (in house, after hours, MCFD) +/- family counselling services.
- FUNCTION**
- Consider advising/writing time off school to coordinate approach. Recommend caregivers consult with school or support services.Follow up with primary physician.
- YOUTH HEALTH**
- Recommend youth health referral if patient over 12 years old, otherwise consult Child Protection Paediatrician and report to MCFD.
  - Review partner's age and criteria for age of consent +/- MCFD considerations.
- PROFESSIONALS**
- Recommend youth health clinic referral, if patient over 12 yrs old, otherwise referral to a pediatrician.
  - Crisis Response Team, or LINK if at BCCH, in regions where existent. If non-existent, or non-eligible, MCFD CYMH Urgent Response (within 3 working days) +/- consultation with psychiatry on call.

### Record Home Page

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event.

Choose action for record

Record ID 1	
Data Collection Instrument	Status
Clinician Information	
HEARTSMAP Tool	
Clinician Recommendations	

Legend for status icon:

Incomplete Incomplete

Unverified

Complete



## fraserhealth HEARTSMAP Report

Form ID: DRDR106452A Rev: July 20, 2016 Page 1 of 4

### Assessment Notes

HOME:

(1) Mild Concerns

Feel stressed

Resources: Social Supports or family counseling services r

### EDUCATION AND ACTIVITIES:

(3) Major Concerns

School year just started

Resources: Educational/Activity issues not yet addressed

### ALCOHOL AND DRUGS:

(2) Moderate Concerns

not interested

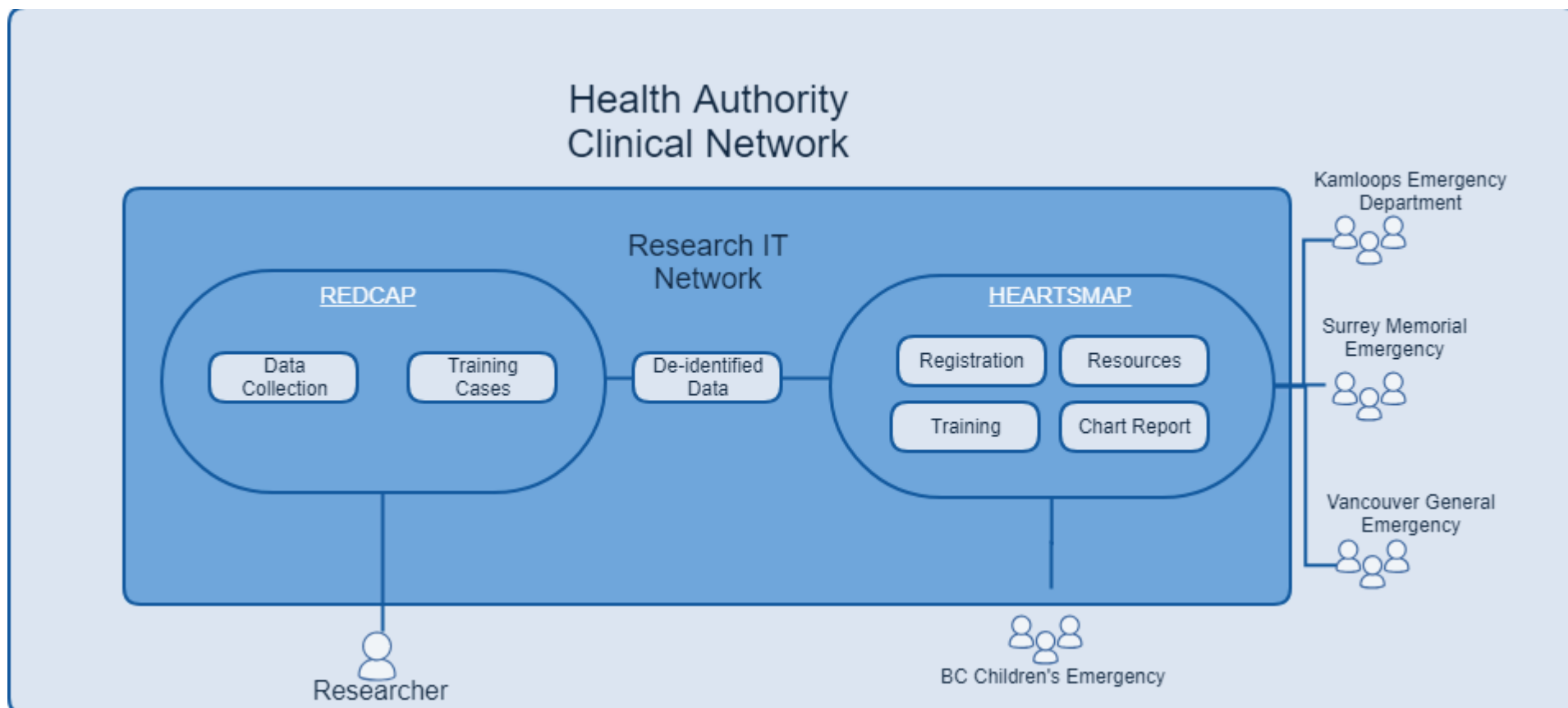
Resources: Substance Use Services or Provincial Youth Co

Place (referred and offered)



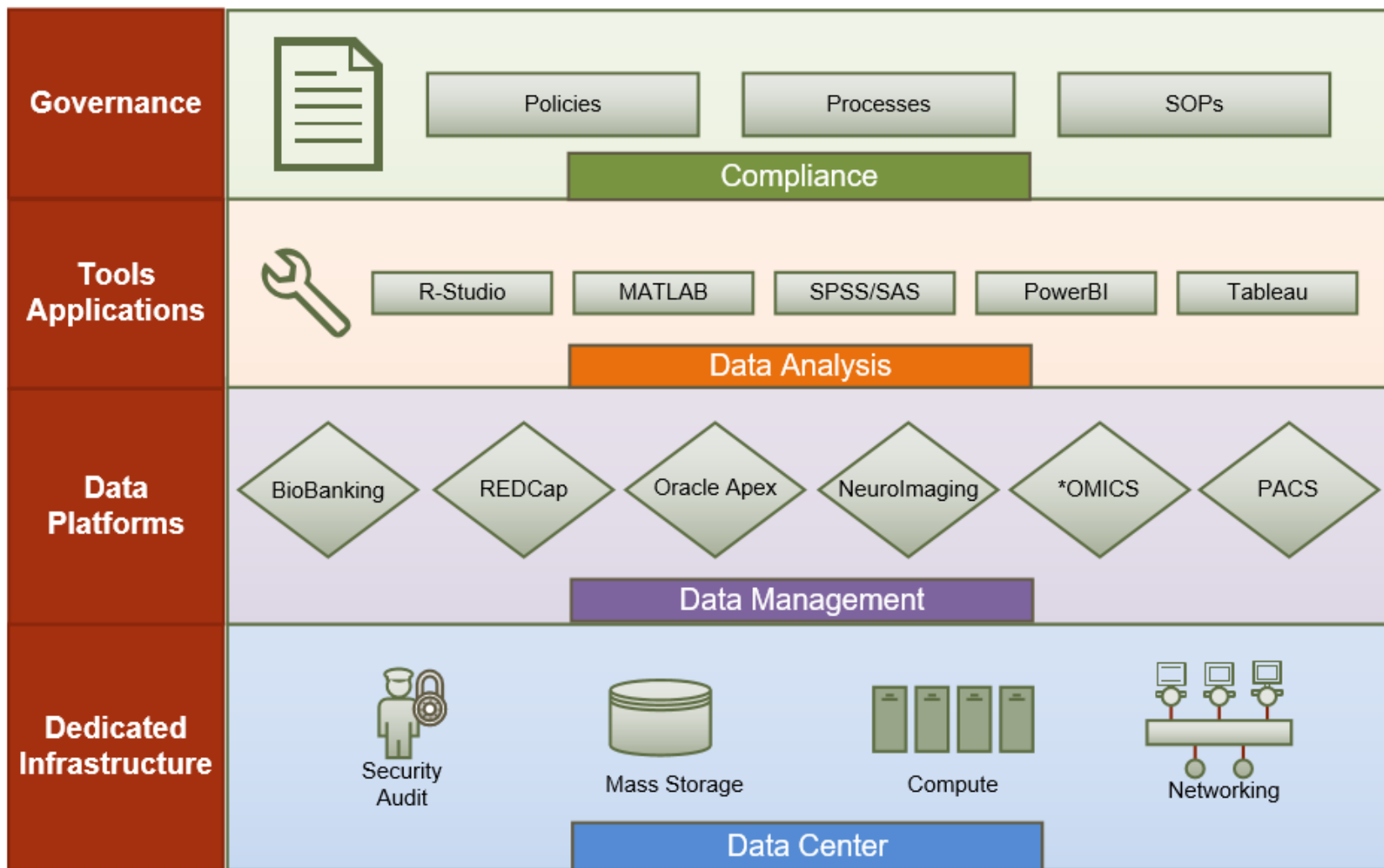
**Stack:** WordPress + Gravity forms + Redcap

**Key enabler:** Research IT network integration into health IT network





## Technology & Data ECOSYSTEM





# Principles

- › Be flexible
  - › Diverse tools and equipment appropriate to users discipline and task
  - › PC/Mac/Linux environment – Hardware (vendor neutral)
- › Foster innovation
  - › Creative in experimentation (POC)
  - › Collaborate with research teams – innovative use of existing tools
- › Accommodate diversity
  - › People, disciplines and tasks are not all the same
  - › BYOD – allow administration
- › Affordable and sustainable services/platforms
  - › Open source tools
  - › Scale solutions & infrastructure
- › Self serve service model
  - › Empower users – IT does not need to control everything
  - › Promote user training and peer learning

## Approach

- › Infrastructure integration with Health Authorities and Academic partners
- › Shared network infrastructure (UBC + PHSA)
- › User Federation and Platform Integration
- › Centralized approach to storage, compute and security
- › Centralized/Multi-tenanted platforms
- › Basic and advanced services model (free vs cost recovery)



# Approach

- › Strong partnership with BC Health Authorities, UBC and other provincial partners
  - › Participation in cross-jurisdiction initiatives
  - › Influence policy and remove barriers to research
- › Data training and Education
  - › Workshops on health data access, management, privacy, Apps, Biostatistics
  - › Data catalogue and Data Advisors
  - › BCCHR Study Catalogue

# Systems

- › Centralized electronic research data collection platform
  - › REDCap
  - › Biobanking: BCCH Biobank, BCCA Ovcare, Individual Research lab/project
  - › PACS Systems (Imaging modalities storage): MRI, Ultra-sound
- › Research Computing
  - › Supporting large data storage & analysis ('Omics, Neuroimaging)
  - › Various data platforms and core facilities
- › Consultation and solution designing for various research initiatives



# Research Technology Needs



# REDCap

- › Infrastructure
  - › Accessible over the internet
  - › Systems and data stored onsite
  - › System validation bi-annually
  - › Manage system wide functionality and access
- › Support
  - › Self-serve support with project consultation
  - › Customizations by request
  - › User helpdesk built into the interface- connected to IT ticket system

## REDCap

- Captures and stores data via data entry, survey and data import
- Allows users to build and customize data collection instruments
- Reporting and exporting capabilities
- Flexible study design



# Medical Staff Wellness Survey – Dr. Theresa Newlove

R.Psych. Head, Department of Psychology BC Children's and Women's Hospital & Sunny Hill Health Centre  
Clinical Investigator, BC Children's Hospital Research Institute, Adjunct Professor, UBC, Department of Psychology

## Survey Goals

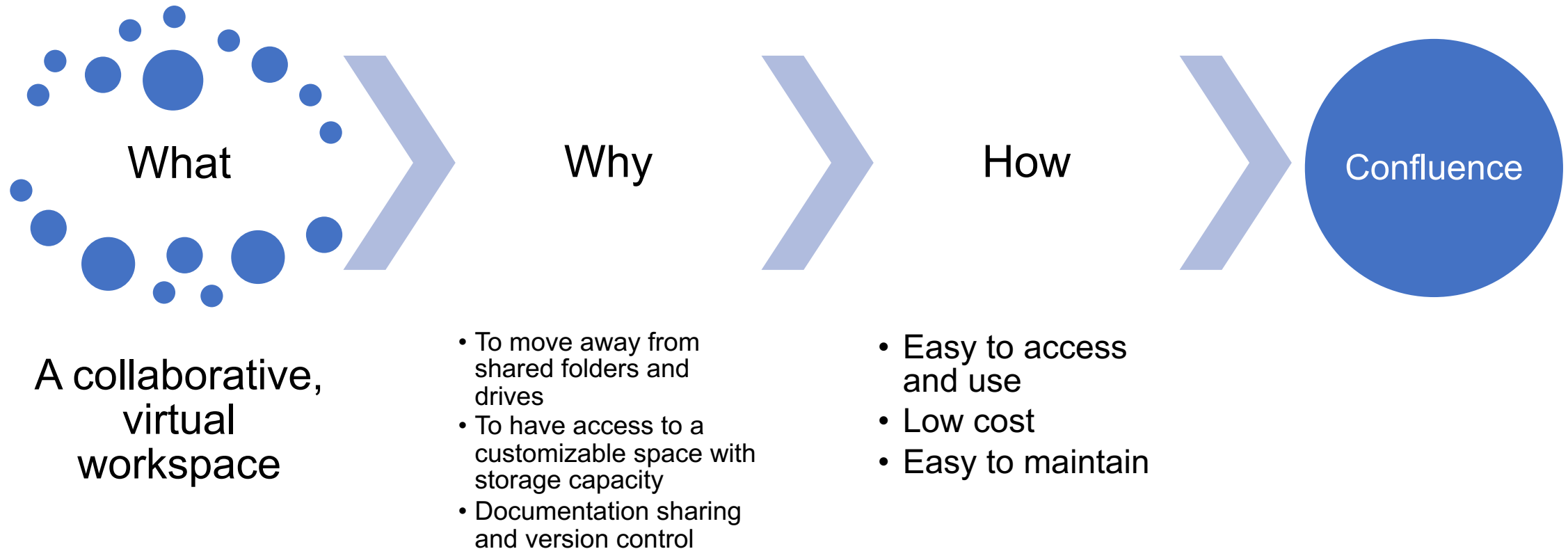
- › Provide a confidential wellness self-assessment tool for medical staff Increase awareness of both burnout and resiliency factors
- › To provide immediate access to wellness resources
- › Proactive approach to physician wellness
- › Promote and integrate wellness initiatives across the organization

## REDCap Functionality

- › Anonymous, web-based survey
- › Included validated, self-assessment tools for burnout and resiliency
- › Calculates survey participants score immediately
- › Provides individual feedback and group comparisons using visualizations
  - › Physicians could “see themselves in the data”
- › Embedded links to wellness resources

Sustainable for IT, for the user, and for collaboration

# Research Technology Needs





# Confluence

- › Infrastructure
  - › Central sharing platform
  - › Accessible with institution account
  - › Research teams are assigned a “space”
    - › Customize and maintain spaces and user permissions
- › Support
  - › Each space is managed by the research team

## Confluence

- Content collaboration software
- Project and document management
- Easy to organize, access and share content
- Customizable

## 3T-MRI Group

### Group Goals

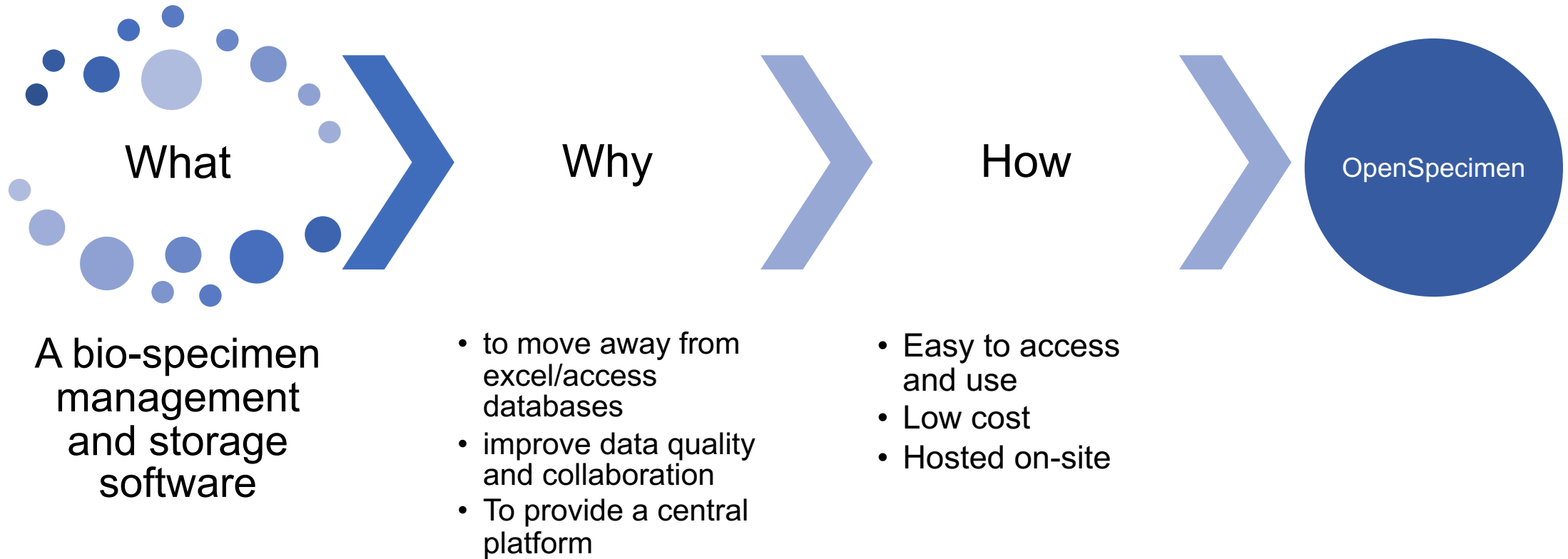
- › To keep track of operational projects and research projects
- › To increase team collaboration
- › To better track project metrics, tasks, and progress
- › To have a central place to store documents

### Confluence Functionality

- › Tags, comments and tasks
- › Ability to 'watch' pages
- › Document versioning
- › Embed graphics and visualizations
- › Generate summary tables and reports



# Research Technology Needs



# OpenSpecimen

- › Infrastructure
  - › Accessible over the intranet
  - › Systems and data stored onsite
- › Support
  - › Data Management Team directly control system wide functions and modules
  - › Training for individual research teams
  - › Technical customizations by request

## OpenSpecimen

- Biospecimen collection and tracking
- Inventory management
- Highly customizable
- Flexible, multi-site structure
- System administration via the user interface



# Biobank

## Project Goals

- › To provide institute wide support for biospecimen focused research
  - › Can provide specimens with rare diagnosis
  - › Consent participants
- › Standardize specimen collection and processing methods

## OpenSpecimen Functionality

- › Highly customizable for institutional and individual researcher needs
- › Flexible design that allows for multiple sites, institutions, and individual protocols
- › Advanced query system for tracking specimens
- › Provides a specimen 'catalog' for researchers to search

## Administrative Support

- › Ticket system
  - › Integration directly with platforms via API
  - › Team management, metric tracking, template responses
- › Training Documentation
  - › Internal knowledgebase built over time
  - › Platform for information and functionality across the software
- › IT and Data Management Team Site
  - › Documentation and project management



# Training Model

- › Self-serve support
  - › Project management is the responsibility of the research team
    - › Allows researchers to control project access, build, and data
    - › Removes the “magic” of technology
- › Data Management Training
  - › Individual consultations
    - › Tailored to specific projects
  - › Group workshops
    - › Hands-on, classroom style

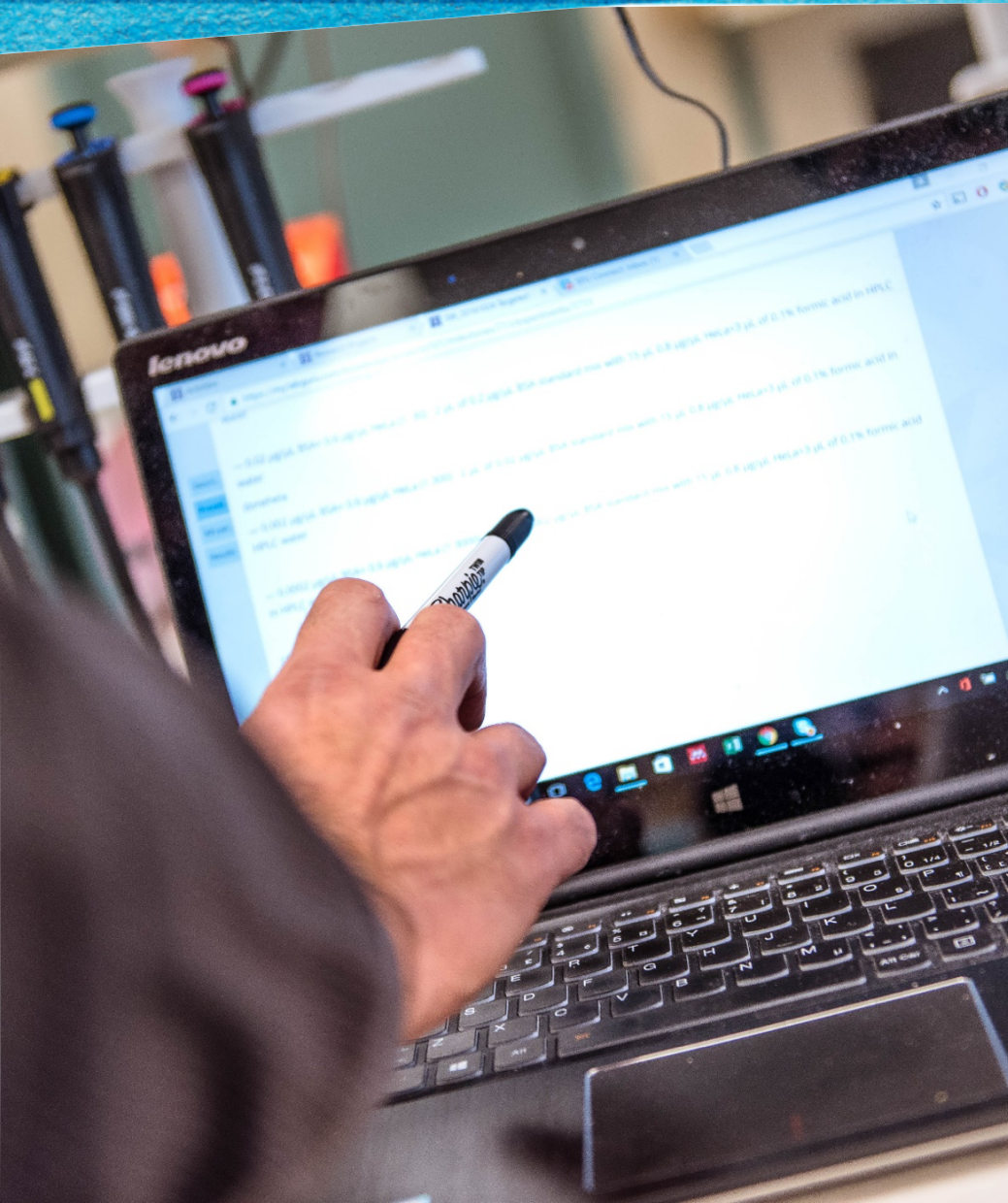
# Challenges

- › Regulatory
  - › Legislation
  - › Ethics Board
- › Health System
  - › EMR that integrates and supports research
  - › Data Access processes
- › Research
  - › Driving value out of Health data
  - › Identifying new and sustaining financial investment for data initiatives and services in academic environment

# Challenges

- › Sustainment
  - › Data, Devices & Systems growth
  - › New technology (NextGenSeq, 3D anatomical printing/visualization)
- › Risk
  - › Lack of services increases data loss risk (Institutional credibility)
  - › Impact to research productivity, rankings, talent and funding
- › Research Funding Model
  - › Tri-council, Foundations, Genome-BC/Can
  - › Data and services need beyond grant/project period





# Thank you

> Questions?