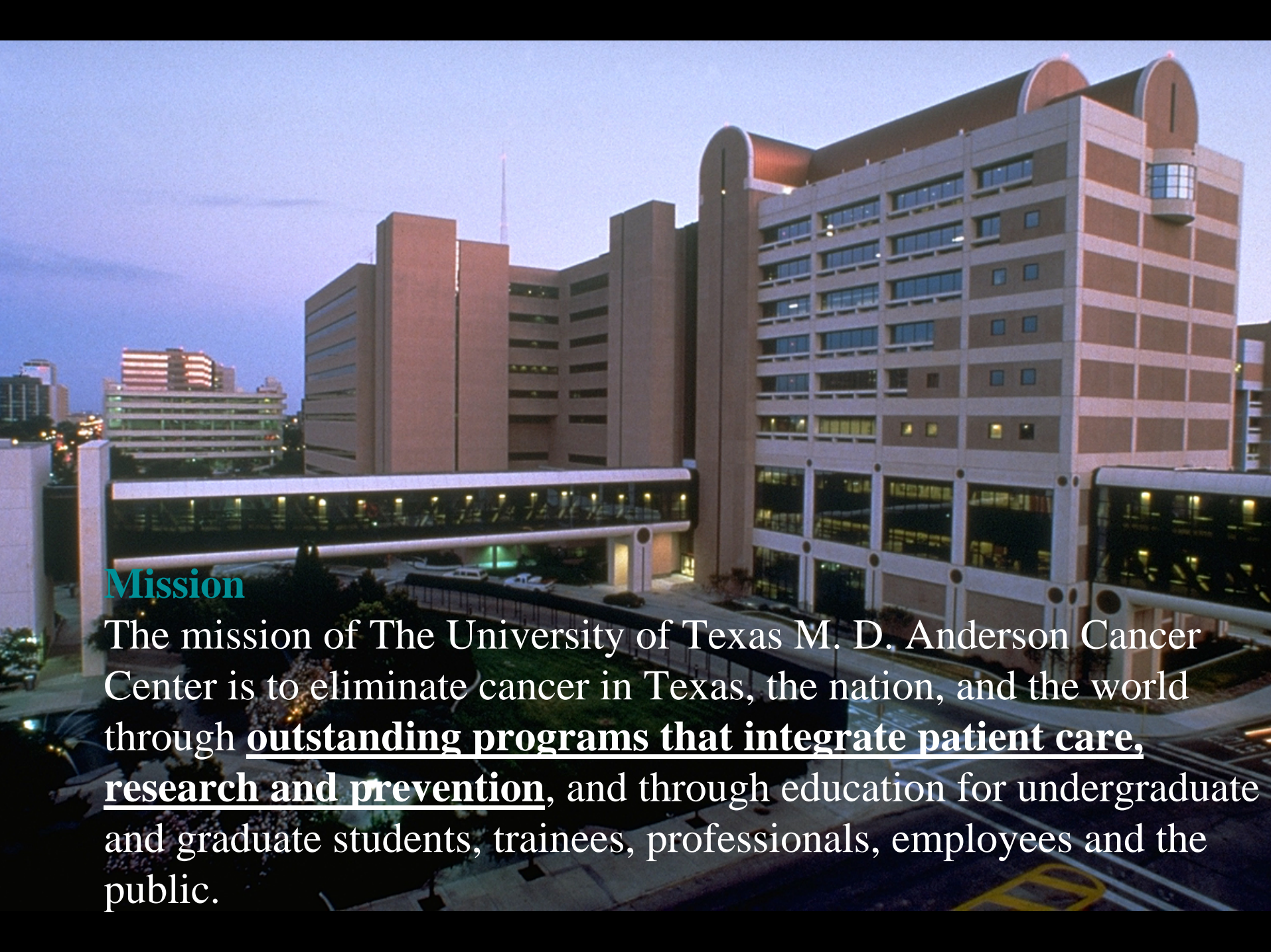


# CANCER RESEARCH INFORMATICS

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## BMT AS A PARADIGM

Roy B. Jones PhD MD  
Department of Blood and Marrow Transplantation  
UT MD Anderson Cancer Center



## Mission

The mission of The University of Texas M. D. Anderson Cancer Center is to eliminate cancer in Texas, the nation, and the world through outstanding programs that integrate patient care, research and prevention, and through education for undergraduate and graduate students, trainees, professionals, employees and the public.

# What the Institutional Mission is Not

---

- Billing
- Scheduling
- Accounting
- Managing Human Resources
- Document Management
- Pharmacy, Radiology, Pathology management
- Food Service
- Parking and Security
- MIS.....

# Why Doesn't Research Have IT Resources ?

---

- Lack of Leadership Support ?
- Lack of IT Commitment ?
- Lack of Funding ?
- Lack of Vision?
  
- **Failure at the IT professional – research professional Interface**

# IT and Clinical Research

---

- EMR - patient centric view
- Research Medical Record (RMR) – protocol centric view
  - Not nightly downloads
  - Not “near on line”
  - Not a silo
  - Not “one size fits all”
  - Not multipatient queries exclusively

# IT and Clinical Research

---

- Why is IT critical for the future of Clinical and Translational Research ?
  - Cost
  - Regulatory and compliance burden
  - Productivity
  - Collaboration

# How the Institution Can Support Research IT

---

- Not a “pretty front end”
- Provide access to institutional data
  - Data standards
    - Promote national standards if available - code
  - Open database systems, encounter based, historical data access
    - Repository/Warehouse
    - Service-oriented architecture
    - Hybrid
  - De-silo !
  - Read/write mentality



Address http://143.111.222.240/

Google Search Web PageRank 0 blocked AutoFill Options

Patient Clinical Schedule Census Hide Queries 10615 Logged in at 04/27/05 12:00

Select by Patient Name Last Name: First Name: Sex: Female Query

Transcribed Documents: 5

346179 - DOE, JOHN

Folder Items	Date	Document T...	Status	Service	Responsible Clinician	Dictator
346179 - DOE, JOHN 55yo M 1/1/1950	09/19/1996	CN	Final	RADIATION THERAPY	COX, JAMES D., MD	LIEBROSS, ROBERT, MD - 06481
Allergies/Reactions: Click to Query	09/19/1996	EB	Final	RADIATION THERAPY	COX, JAMES D., MD	LIEBROSS, ROBERT, MD - 06481
Unread Radiology Exams: 0	09/19/1996	PM	Final	RADIATION THERAPY	COX, JAMES D., MD	LIEBROSS, ROBERT, MD - 06481
Radiology Reports: 0	09/19/1996	CO	Final	RADIATION THERAPY	COX, JAMES D., MD	COX, JAMES D., MD - 00127
Diagnostic Images: 0	09/19/1996	SS	Final	RADIATION THERAPY	COX, JAMES D., MD	LIEBROSS, ROBERT, MD - 06481
Laboratory: 0						
Pathology Reports: 0						
Transcribed Documents: 5						
Anesthesia Preop: 0						
Anesthesia/PACU Record: 0						
Scanned Documents: 0						
Cardiology: 0						
Pulmonary Function Tests: 0						
Pulmonary Function (Xenon-133): 0						
Vital Signs: 0						
Treatment Plans: 0						
Outpatient Pharmacy: 0						
Pharmacy (IP & ATC)						
Historical IP Pharmacy: 0						
FlowSheet: 1						
Schedule: 0						
Scheduled Surgeries: 0						
Involved Providers: 1						
Protocols: 0						
Tumor Registry: 1						
Durable Medical Equipment: 0						
Respiratory Care: 0						
Medical Photographs: 0						
Transcribed Preliminary Documents: 25						
Recent Patients: 28						
My Patients						
Clinical Schedule						
Census						
Surgery Schedule: 85						
Name Search: 4						

09/19/96

RADIATION ONCOLOGY INITIAL SUMMARY

PRIMARY SITE AND HISTOPATHOLOGY: Right acetabular fracture.

STAGE:

HISTORY: The patient is approximately a 30-year-old white male who on 09/14 was involved in a motor vehicle accident in which he suffered a right tibial plateau fracture, right acetabular fracture and dislocation and head trauma consisting of multiple contusions in his left temporal and right temporal lobes of his brain and skull fractures in his right frontal and left temporal bones as well as subarachnoid hemorrhage. On 09/18, he underwent an open reduction and internal fixation of his right acetabulum and presents to M. D. Anderson from Hermann Hospital for postoperative irradiation of his right hip to prevent formation of heterotopic bone. Patient's identity remains unknown and he is unresponsive at this time.

SUMMARY OF PERTINENT X-RAY OR LABORATORY FINDINGS:

PHYSICAL FINDINGS:

RISKS OF RADIATION THERAPY: The patient is unresponsive at this time and his identity is unknown.

BASIC TREATMENT PLAN: The plan is to treat this patient using an AP field to his right hip using 18 MV photons and a total dose of 800 cGy in one fraction.



# Institutional Systems

Clinical Lab

ADT

Pathology

Financial

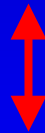
Radiology



Governance  
Data Dictionary

Shared Data  
Repository

Authorities



# Research Systems

BMT

Solid Tumors

Hematopoietic Tumors

Labs

# Special Case Institutional Research Systems

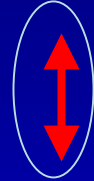
IRB

Compliance

Research Tracking

Accreditation

NIH

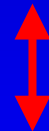


Governance

Data Dictionary



Authorities



## Research Systems

BMT

Solid Tumors

Hematopoietic Tumors

Labs

# Alternative Models



OR

Research Systems



# Which Model is Best ?

---

- Decision depends on institutional variables
  - Politics as important as IT optimization
  - Cooperation of “satellite IT kingdoms”
  - IT savvy of managers/administrators
  - Patience of staff
- Without institutional data integration and standardization, research IT is doomed

# Goals of BMT Research Systems

---

- Interface data whenever possible
- Point of care (POC) data entry [(s)he who generated the data enters it]
- Front end programs which mimic clinical research workflow
- Front end systems which are protocol-centric
  - Department-based customization
  - Web-based architecture
  - ? role of “ IT business process consultant”
  - Need for informed department-based IT liaison

# PRIORITIES FOR BMT IT DEVELOPMENT

---

- Enhancement of research
  - Improved protocol enrollment
  - Increased data with improved quality
- Enhancement of business priorities
  - Improved level-of-service justification
  - Increased level-of-service data capture
  - Improved contracting/budgeting
- Improved efficiency
  - No increase workload for physicians or physician-support staff

# DATA SYSTEMS AND EXCHANGES

Clinical Research Workflow

Institutional Clinical  
Research Computing

Case Report Form

*iKnowmed* (?!)  
(*COIS*?)

*CRIS/SDR*  
Clinicstation/CARE

BMTWeb  
Java

“view”

Cell Processing Lab

Department Webpage

LabWorks  
*Stemsoft*

BMTWeb  
*Oracle Database*

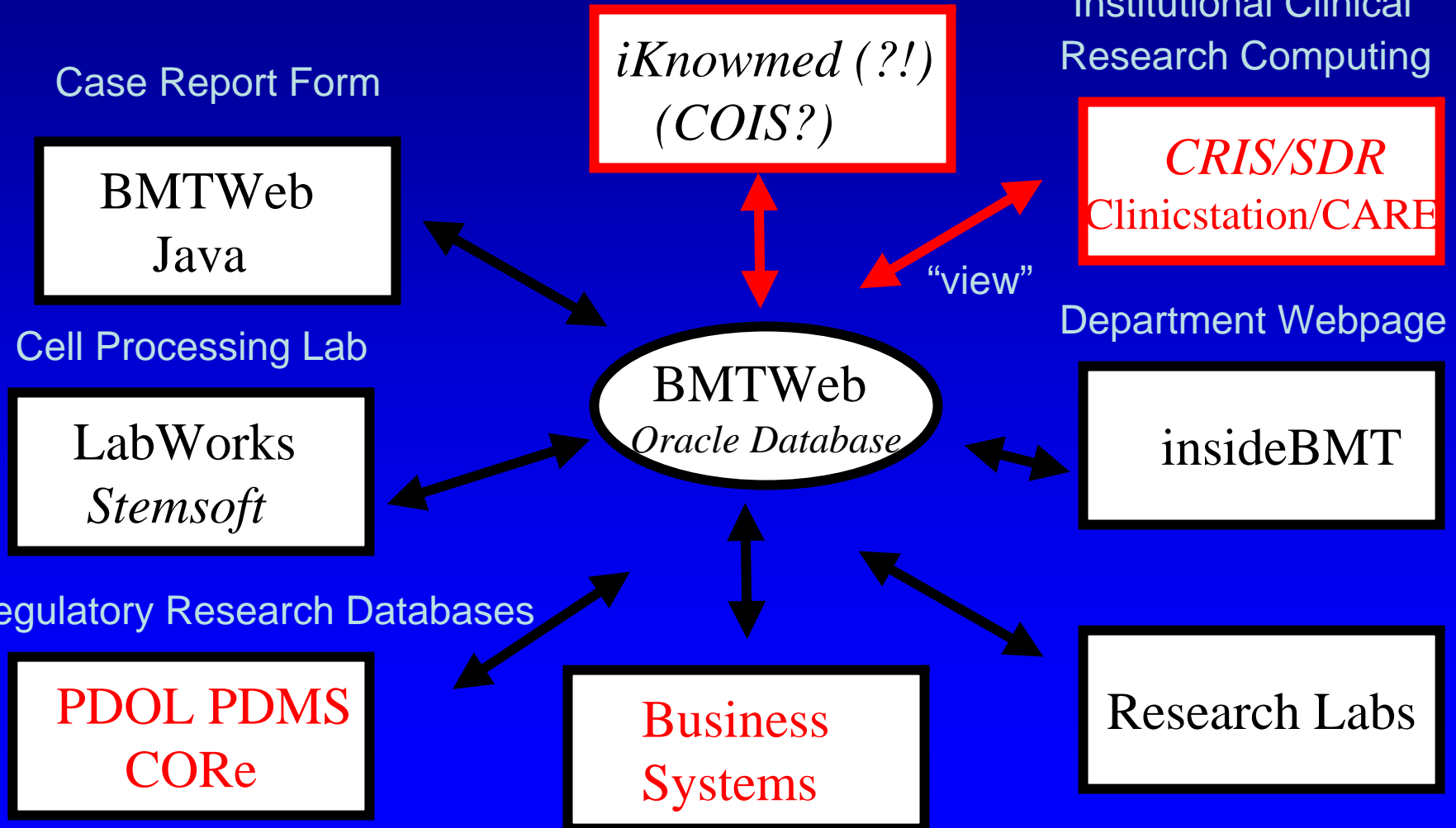
insideBMT

Regulatory Research Databases

PDOL PDMS  
CORe

Business  
Systems

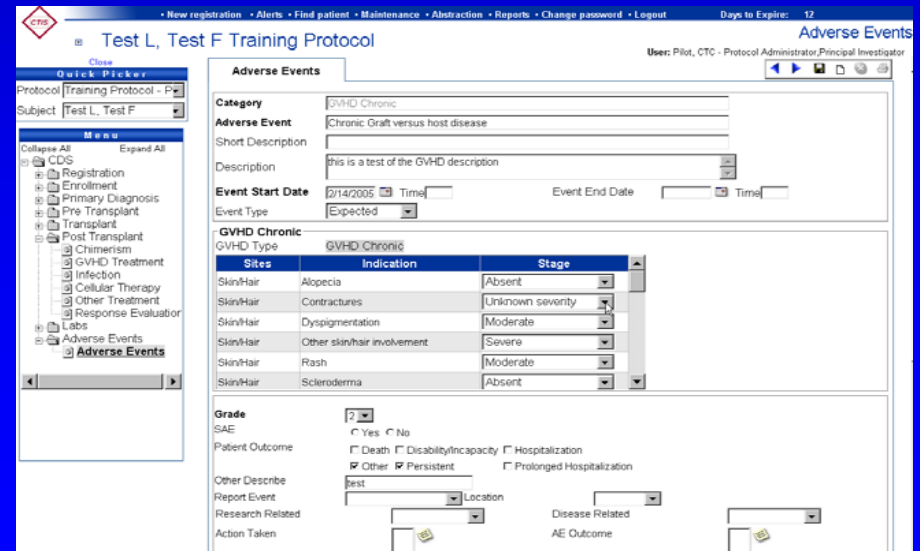
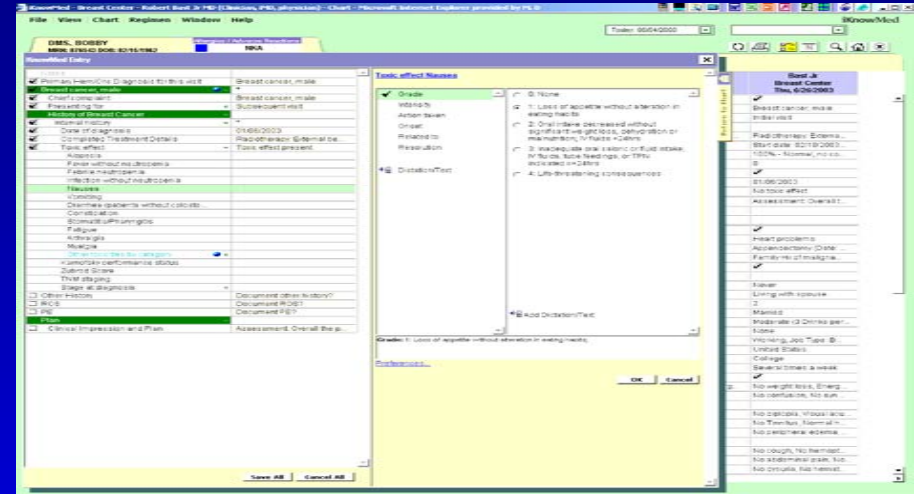
Research Labs



# BMT Architecture

## What We Have

- iKnowmed or COIS
  - Protocol-oriented design
  - Knowmed concept (D Simborg)
  - Clinical note and billing output
  - iKnowmed Needs BMT buildout





DMS, BOBBY  
MRN: 876543 DOB: 02/15/1962

Allergies / Adverse Reactions  
NKA

KnowMed Entry

Notes	
<input checked="" type="checkbox"/> Primary Hem/Onc Diagnosis for this visit	Breast cancer, male
<input checked="" type="checkbox"/> Breast cancer, male	*
<input checked="" type="checkbox"/> Chief complaint	Breast cancer, male
<input checked="" type="checkbox"/> Presenting for	Subsequent visit
History of Breast Cancer	
<input checked="" type="checkbox"/> Interval history	*
<input checked="" type="checkbox"/> Date of diagnosis	01/06/2003
<input checked="" type="checkbox"/> Completed Treatment Details	Radiotherapy: External be...
<input checked="" type="checkbox"/> Toxic effect	Toxic effect present
Alopecia	
Fever without neutropenia	
Febrile neutropenia	
Infection without neutropenia	
Nausea	
Vomiting	
Diarrhea (patients without colosto...	
Constipation	
Stomatitis/Pharyngitis	
Fatigue	
Arthralgia	
Myalgia	
Other toxicities by category	
Karnofsky performance status	
Zubrod Score	
TNM staging	
Stage at diagnosis	
<input type="checkbox"/> Other History	Document other history?
<input type="checkbox"/> ROS	Document ROS?
<input type="checkbox"/> PE	Document PE?
Plan	
<input type="checkbox"/> Clinical Impression and Plan	Assessment: Overall the p...

Save All Cancel All

Toxic effect Nausea

Grade

Intensity

Action taken

Onset

Related to

Resolution

Dictation/Text

0: None

1: Loss of appetite without alteration in eating habits

2: Oral intake decreased without significant weight loss, dehydration or malnutrition; IV fluids <24hrs

3: Inadequate oral caloric or fluid intake; IV fluids, tube feedings, or TPN indicated =>24hrs

4: Life-threatening consequences

Add Dictation/Text

Grade: 1: Loss of appetite without alteration in eating habits;

Preferences...

OK Cancel

Bast Jr Breast Center Thu, 6/26/2003	
<input checked="" type="checkbox"/>	Breast cancer, male
<input type="checkbox"/>	Initial visit
...	Radiotherapy: Externa...
<input type="checkbox"/>	Start date: 02/10/2003...
<input type="checkbox"/>	100% - Normal, no co...
<input type="checkbox"/>	0
<input checked="" type="checkbox"/>	01/06/2003
<input type="checkbox"/>	No toxic effect
<input type="checkbox"/>	Assessment: Overall t...
<input checked="" type="checkbox"/>	Heart problems
<input type="checkbox"/>	Appendectomy (Date: ...
<input checked="" type="checkbox"/>	Family Hx of maligna...
<input type="checkbox"/>	Never
<input type="checkbox"/>	Living with spouse
<input type="checkbox"/>	2
<input type="checkbox"/>	Married
<input type="checkbox"/>	Moderate (3 Drinks per...
<input type="checkbox"/>	None
<input type="checkbox"/>	Working, Job Type: B...
<input type="checkbox"/>	United States
<input type="checkbox"/>	College
<input type="checkbox"/>	Several times a week
<input checked="" type="checkbox"/>	No weight loss, Energ...
<input type="checkbox"/>	No confusion, No syn...
<input type="checkbox"/>	No diplopia, Visual acu...
<input type="checkbox"/>	No Tinnitus, Normal h...
<input type="checkbox"/>	No peripheral edema, ...
<input type="checkbox"/>	No cough, No hemopt...
<input type="checkbox"/>	No abdominal pain, No...
<input type="checkbox"/>	No dysuria, No hemat...



# Test L, Test F Training Protocol

User: Pilot, CTC - Protocol Administrator, Principal Investigator



Close

## Quick Picker

Protocol Training Protocol - P

Subject Test L, Test F

## Menu

Collapse All Expand All

- [-] CDS
  - [-] Registration
  - [-] Enrollment
  - [-] Primary Diagnosis
  - [-] Pre Transplant
  - [-] Transplant
  - [-] Post Transplant
    - Chimerism
    - GVHD Treatment
    - Infection
    - Cellular Therapy
    - Other Treatment
    - Response Evaluation
  - [-] Labs
  - [-] Adverse Events
    - Adverse Events**

## Adverse Events

**Category** GVHD Chronic

**Adverse Event** Chronic Graft versus host disease

Short Description

Description this is a test of the GVHD description

**Event Start Date** 2/14/2005 Time Event End Date Time

Event Type Expected

### GVHD Chronic

GVHD Type GVHD Chronic

Sites	Indication	Stage
Skin/Hair	Alopecia	Absent
Skin/Hair	Contractures	Unknown severity
Skin/Hair	Dyspigmentation	Moderate
Skin/Hair	Other skin/hair involvement	Severe
Skin/Hair	Rash	Moderate
Skin/Hair	Scleroderma	Absent

**Grade** 2

SAE  Yes  No

Patient Outcome  Death  Disability/Incapacity  Hospitalization  Other  Persistent  Prolonged Hospitalization

Other Describe test

Report Event Location

Research Related Disease Related

Action Taken AE Outcome

# BMT Architecture

## What We Have

- BMTWeb Java
  - Data manager data input
  - CRF format
  - Can evolve from data input to audit format

The screenshot displays a web-based patient record form for a BMT patient. The title bar indicates the patient ID is T89009(MRN) and the diagnosis is AML / MDS. The form is organized into several sections:

- Init Dx:** Includes fields for Date, Dx (dropdown), Did AML arise from previous MDS (dropdown), Transformation date, Histology (dropdown), Other (text), and Findings (text).
- Cytogenetics:** Includes fields for Tested Date, # cells counted, Abnormal? (dropdown), Abnormal cells(%) (text), Risk Cat. (dropdown), and a Description field.
- Other Fields:** Includes Dx Lab (with a Zoom button), B symptoms (dropdown, with a Zoom button), Spleen size (dropdown), CHS? (dropdown), Other sites (text), Is this a treatment related MDS? (dropdown), Is this a treatment related AML? (dropdown), Smoker (dropdown), # of pack years (text), Prior Malignancy Date (text), and Transplant for prior malignancy (dropdown).

At the bottom, there are fields for "Init Dx record created by" and "Last modified by", and a footer with "Save" and "BMT Admin" buttons.



Patient Init Diag Tx History DX Sites Assessment Workup Serology Treatment Recov Event Outcome Note

Init Dx

Date  Dx  Did AML arise from previous MDS

Transformation date  Histology  Other

Findings

Cytogenetics

Data field: INITDX.DX\_FINDING. Data type: Character string. Data length: 1000

Tested Date  # cells counted  Abnormal?  Abnormal cells(%)  Risk Cat.

Description

Dx Lab  Zoom  B symptoms  Zoom  Spleen size

Was extramedullary Disease present in:

CNS?  Other sites

Is this a treatment related MDS?  Is this a treatment related AML?

Smoker  # of pack years

Prior Malignancy Date   Transplant for prior malignancy

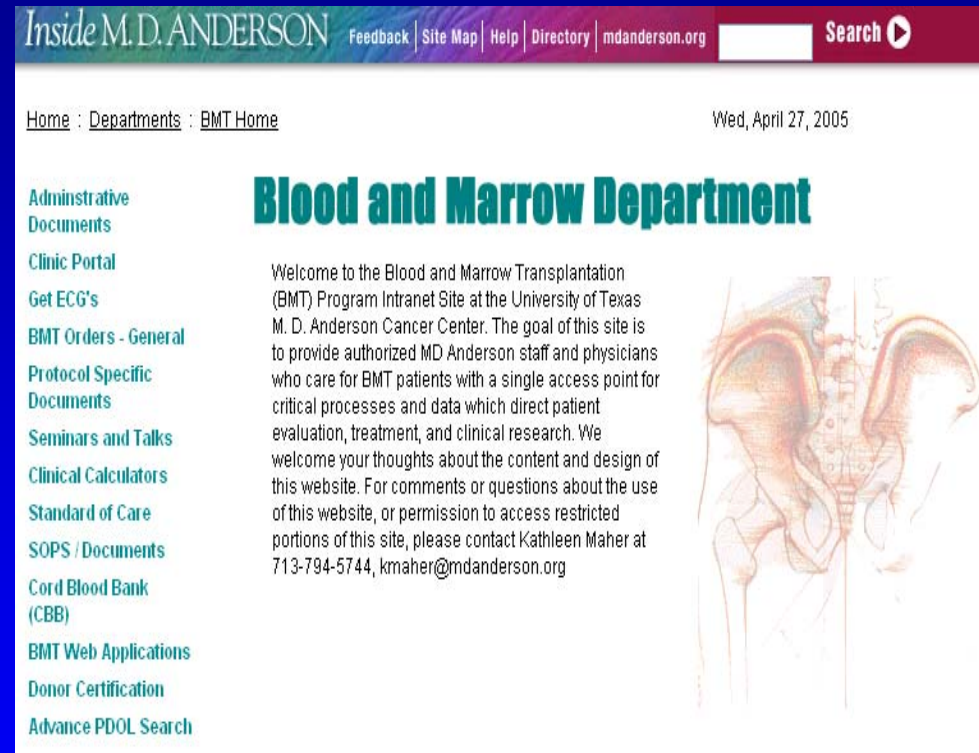
Init Dx record created by Last modified by

Save BMT Admin

# BMT Architecture

## What We Have

- InsideBMT
  - Departmental Web page integrated into the insideMDAnderson intranet
  - Useful for support personnel not directly involved in patient care



The screenshot shows the website for the Blood and Marrow Department at M.D. Anderson Cancer Center. The header includes the text "Inside M.D. ANDERSON" and navigation links for "Feedback", "Site Map", "Help", "Directory", and "mdanderson.org". A search bar is located on the right. The main content area features a sidebar with a list of links: "Administrative Documents", "Clinic Portal", "Get ECG's", "BMT Orders - General", "Protocol Specific Documents", "Seminars and Talks", "Clinical Calculators", "Standard of Care", "SOPS / Documents", "Cord Blood Bank (CBB)", "BMT Web Applications", "Donor Certification", and "Advance PDOL Search". The main heading is "Blood and Marrow Department" in a large, bold, teal font. Below the heading is a welcome message: "Welcome to the Blood and Marrow Transplantation (BMT) Program Intranet Site at the University of Texas M. D. Anderson Cancer Center. The goal of this site is to provide authorized MD Anderson staff and physicians who care for BMT patients with a single access point for critical processes and data which direct patient evaluation, treatment, and clinical research. We welcome your thoughts about the content and design of this website. For comments or questions about the use of this website, or permission to access restricted portions of this site, please contact Kathleen Maher at 713-794-5744, kmaher@mdanderson.org". To the right of the text is a stylized, semi-transparent illustration of a human torso showing the skeletal structure and internal organs, with a focus on the pelvic and abdominal regions.

[Administrative Documents](#)[Clinic Portal](#)[Get ECG's](#)[BMT Orders - General](#)[Protocol Specific Documents](#)[Seminars and Talks](#)[Clinical Calculators](#)[Standard of Care](#)[SOPS / Documents](#)[Cord Blood Bank \(CBB\)](#)[BMT Web Applications](#)[Donor Certification](#)[Advance PDOL Search](#)

## Blood and Marrow Department

Welcome to the Blood and Marrow Transplantation (BMT) Program Intranet Site at the University of Texas M. D. Anderson Cancer Center. The goal of this site is to provide authorized MD Anderson staff and physicians who care for BMT patients with a single access point for critical processes and data which direct patient evaluation, treatment, and clinical research. We welcome your thoughts about the content and design of this website. For comments or questions about the use of this website, or permission to access restricted portions of this site, please contact Kathleen Maher at 713-794-5744, [kmaher@mdanderson.org](mailto:kmaher@mdanderson.org)



User: dcouriel	CM:	<b>Patient Info</b>	
Date: 4/19/2005 9:45:21 AM	MDACC:	SEX: F	DOB: 56
PT:	Last Name:	First Name:	

Consult_Date: 1/12/2005	PAC: KG	PAS: rgarcia
DX: LYMPH	Doctor: Couriel	

Estimate Info	Insurance Info	LMN Tracking	Cobra Tracking	Template Tracking PAS
---------------	----------------	--------------	----------------	-----------------------

Approvals	Donor Search Approval	Denials	Appeals
Verbal: 3/17/2005	HLA MOM: <input type="checkbox"/>	Verbal_Denial:	1st Ver Appeal:
LOA/Medical:	HLA DAD: <input type="checkbox"/>	Verbal_Den 2:	2nd ver Appeal:
LOA Start Date: 3/17/2005	HLA SIBS: <input checked="" type="checkbox"/> Yes # sibs: 3	1st Denial:	1st Appeal:
LOA End Date: 3/17/2006	HLA KIDS: <input type="checkbox"/> # kids:	2nd Denial:	2nd Appeal:
Financial APP: 3/17/2005	HLA OTHER: <input type="checkbox"/> #other:	3rd Denial:	3rd Appeal:
Verbal Manager:	Donor Search Approved: <input type="checkbox"/>	Final Denial:	
Admin o-ride:	Donor Work Up Approved: <input type="checkbox"/>	Overturn Date:	
	Cord Search Approved: <input type="checkbox"/> No	Recovered:	
	Cord Search Workup: <input type="checkbox"/> No		

Auth Code: FA	Clinical Code: ST/1st	Status Overall: Complete	Transplant date:
---------------	-----------------------	--------------------------	------------------

**Comments** BC/LA - Financially approved for Auto/03-0123/03-0242. Patient will not be admitted for mobilization until around July. W8/W. Rg 04/01/05

Comments Date: 4/1/2005      Death date:

Next LMN      Prev LMN      1      Save      Add New LMN

Entry Use: rgarcia      Entry Date: 1/12/2005 4:58:46      Edit: rgarcia      Edit date: 4/19/2005 9:44:32 AM

Record: 1 of 1



# Financial Approvals

**User** dcouriel  
**Date** 4/19/2005 8:14:11 AM

**Current Patients** dcouriel

DBL click on MDACC to select a current PT or Here -> for a new search

MDACC	Last	First	Auth Status:	LMN_TO_INS	CM
			INS WAITING FOR ANY OF THE FOL	3/1/2005	Guthry
	Last Contact 4/13/2005	One Health (URN) - Auto w/mobil 03-0123/03-0242. Home physician has PFT scheduled for 04/06/05. Insurance denied claim due to investigational. Gave to Rose H for Appeal. rg 04/05/05 /// 4/11/05 Rec'd the pt's case. ( I was on vacation). // 4/13/05 spoke with pt and discussed the appeal process. Pt wants us to appeal the case. rh 4/13/05			
			FINANCIALLY CLEARED BY PAS	1/19/2005	Guthry
	Last Contact 4/11/05	BC/LA - Financially approved for Auto/03-0123/03-0242. Patient will not be admitted for mobilization until around July. W&W. Rg 04/01/05			
			INS VERBALLY APPROVED TRANSPL	10/15/2003	Champagne
	Last Contact 8/9/2004	forward to Steve PAC to assist on receiving copy of LOA. Unable to reach patient by phone. Sbasquez 08-09-04			
			FINANCIALLY CLEARED BY PAS	7/26/2004	Guthry
	Last Contact 4/1/2005	Medicaid - Financially approved for Allo unrel/01-200. Patient scheduled to RTC 4/20/05. Donor Found. Watch and Wait. Rg 04/01/05			
			FINANCIALLY CLEARED BY PAS		Guthry
	Last Contact	Medicare - Financially approved for Auto/SOC-Beam. Patient is not scheduled to RTC as of today.			

Record:        of 70

# Report Screen for Docs



# What We've Learned

---

- Data integration is critical for success
- Standard “business” IT solutions often require modification for the research environment
- “Out of the box” pretty front ends usually fail
- Learning the research environment is critical
  - Identify an IT savvy medical collaborator
  - Train in-house IT staff in clinical focus areas and have them work there
- Be liberal when defining who is the “customer” as they will define success

# Acknowledgements

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- BMT
  - Charles Martinez
- MDACC
  - Lynn Vogel
  - Don Lyons
  - Randy Millikan
  - Kevin McEnergy
- U Colorado HSC
  - Steve Clark
- CTIS
- NCI
  - Michelle Christian
- Duke
  - Ed Hammond
  - Eugene Stead