WU ADRC DATA INTEGRATION AND SHARING: PLAN & PROGRESS

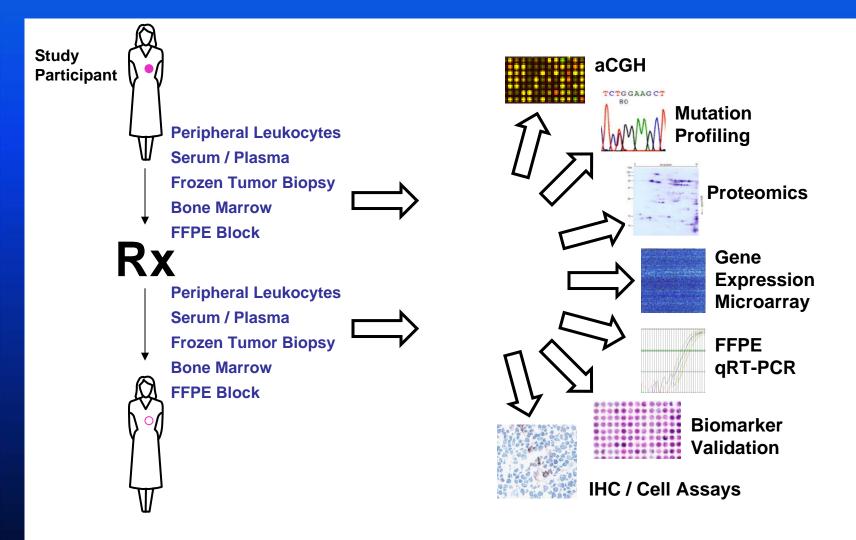
http://nagarajanlab.wustl.edu



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*Dr. Nagarajan is on the Scientific Advisory Board of Persistent Systems. Persistent Systems does not fund Dr. Nagarajan's research.

Translational Research Paradigm



WU Alzheimer's Disease Research Center Cores

• Clinical Core

 Patient demographic information, family history, health history, depression inventories, physical examination, standard cognitive tests, and CDR

• Biomarkers Core

 Fasting plasma and cerebrospinal fluid- Levels of total protein, hemoglobin A1C, homocysteine, folate, Aβ, tau, apoE, and other biomarkers

Genetics Core

Non-fasting blood, plasma, serum, buffy coat, and DNA during the initial visit and every 3 years thereafter for genotyping APOE and other genetic risk factors

Neuropathology Core

 Post-mortem frozen and fixed brain tissue- Quantitation of senile plaques, neurofibrillary tangles, neuron counts, amyloid angiopathy, Lewy bodies, and vascular pathology

Psychometric Core

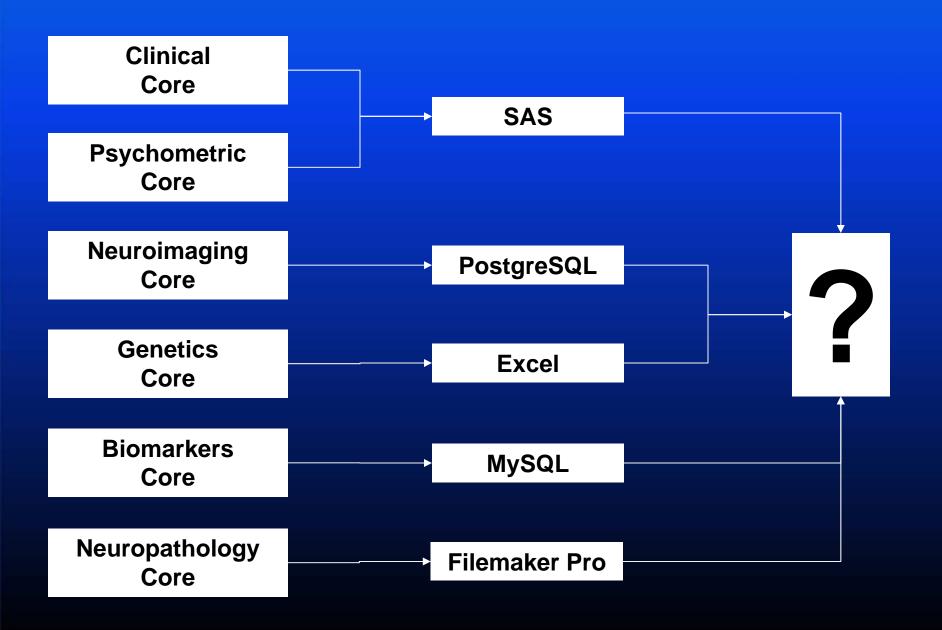
 Primary, working, episodic, and semantic memory, abstract reasoning, visuospatial/visuoconstructive dysfunction, psychomotor deficits

Neuroimaging Core

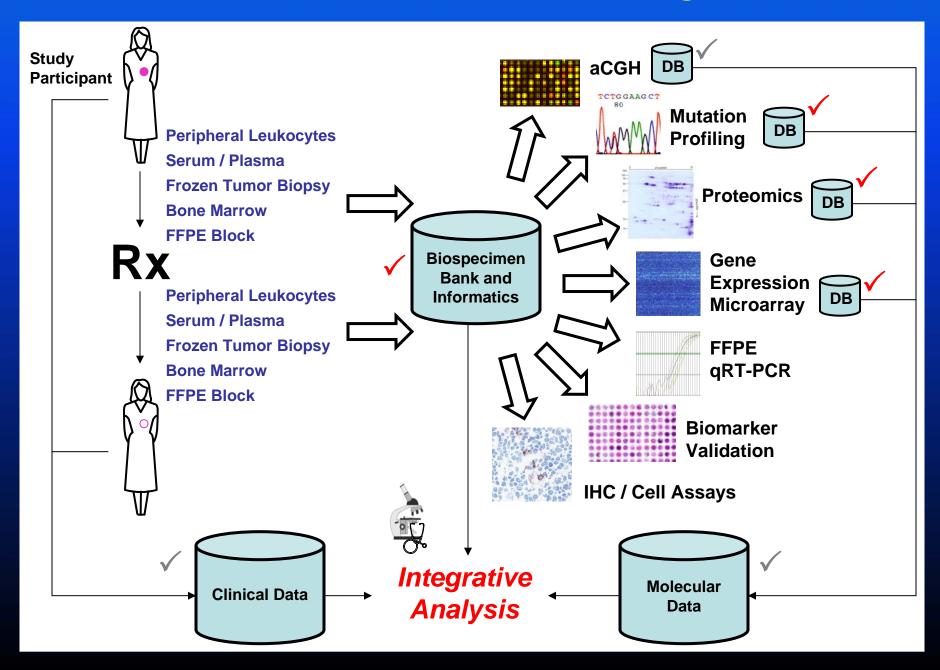
 MRI (3D T1- and T2-weighted scans, diffusion-weighted scans, echo-planar imaging scans); Amyloid PET scan data and derived images

Core	Participants	Encounters	Biospecimens
Clinical	3,489	11,486	N/A
Psychometric	3,036	9,554	N/A
Neuroimaging	716	1,346	N/A
Neuropathology	1,255	1,255	~62,000
Genetics	3,669	5,467	~170,000
Biomarkers	465	497	~25,000

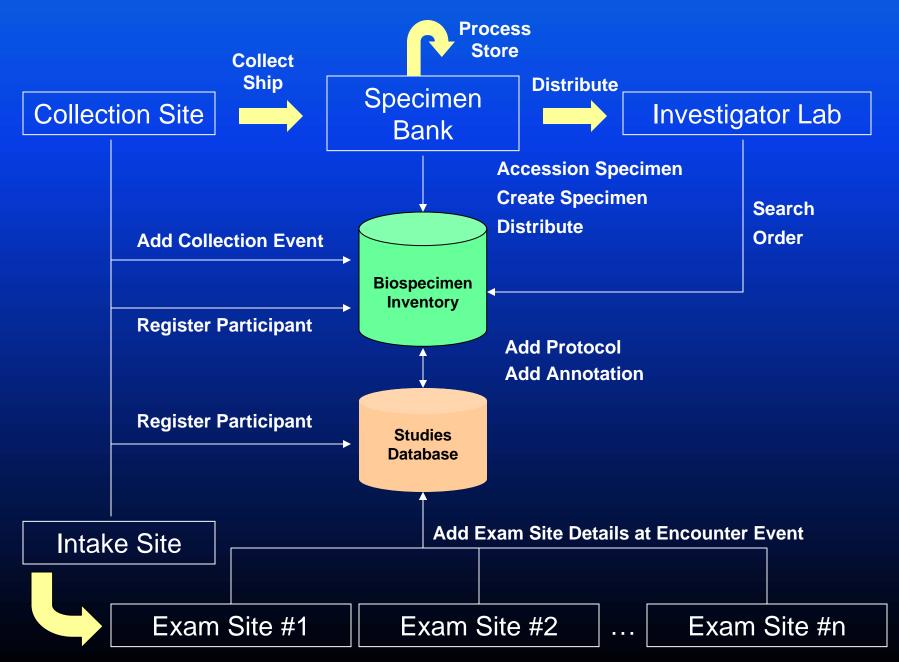
WU ADRC Data Integration Problem



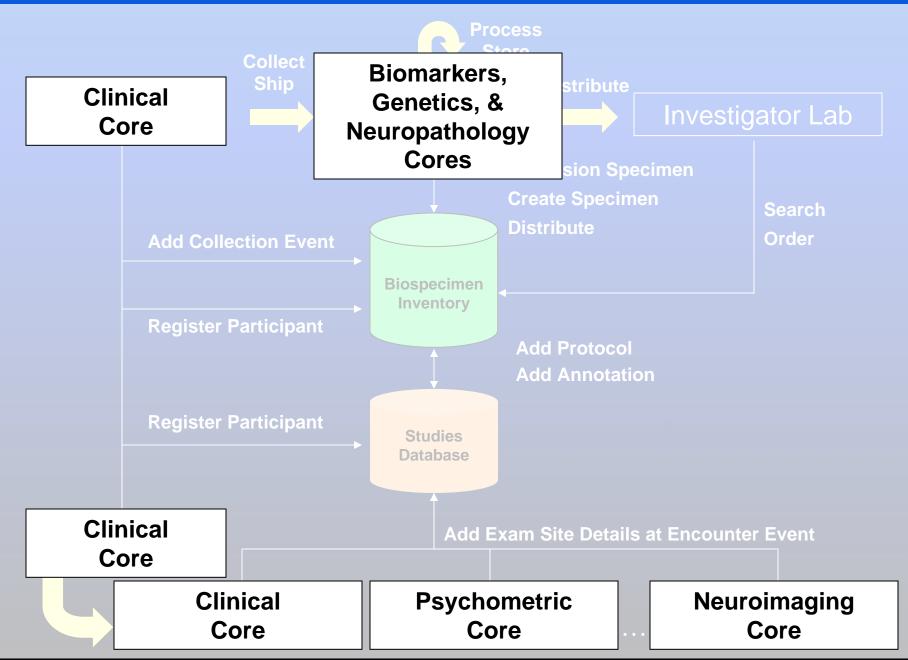
Translational Research Paradigm



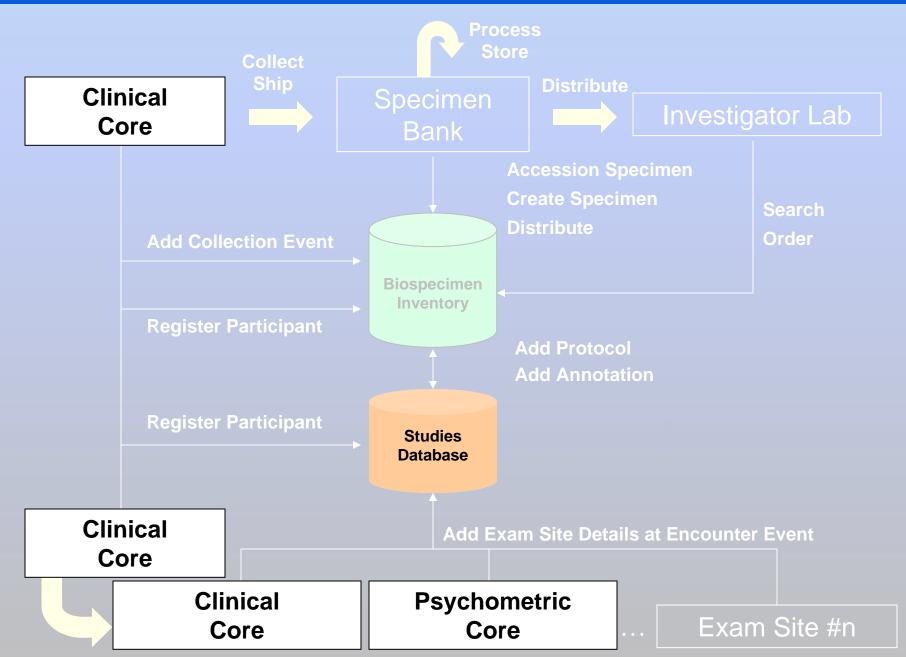
Workflow of a Translational Research Study



Workflow of the WU ADRC



Clinical Studies Data Management



ClinPortal: Representing & Storing Clinical Studies

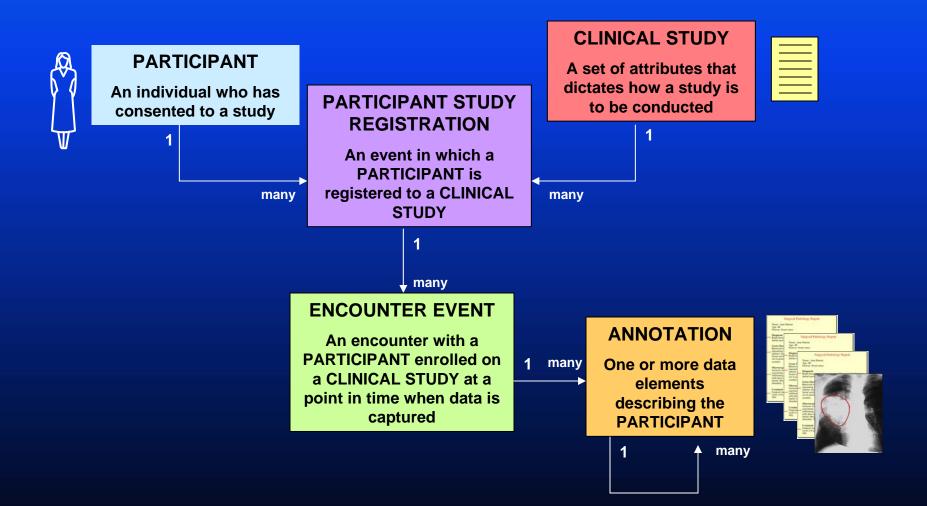
 Robust and scalable clinical studies management system

• End user graphical design of clinical case reports

• Automatic generation of forms for data entry

• Graphical interface to query and download study data

ClinPortal Concepts



ClinPortal Study Definition

- Define clinical study encounter events
- Define data elements (attributes or variables) to capture at each encounter event
- Model data elements as appropriate to the biomedical domain (e.g. group biomarkers together and organize physical exam findings per anatomic location)
- Create forms containing variables
- Associate form(s) to one or more encounter events

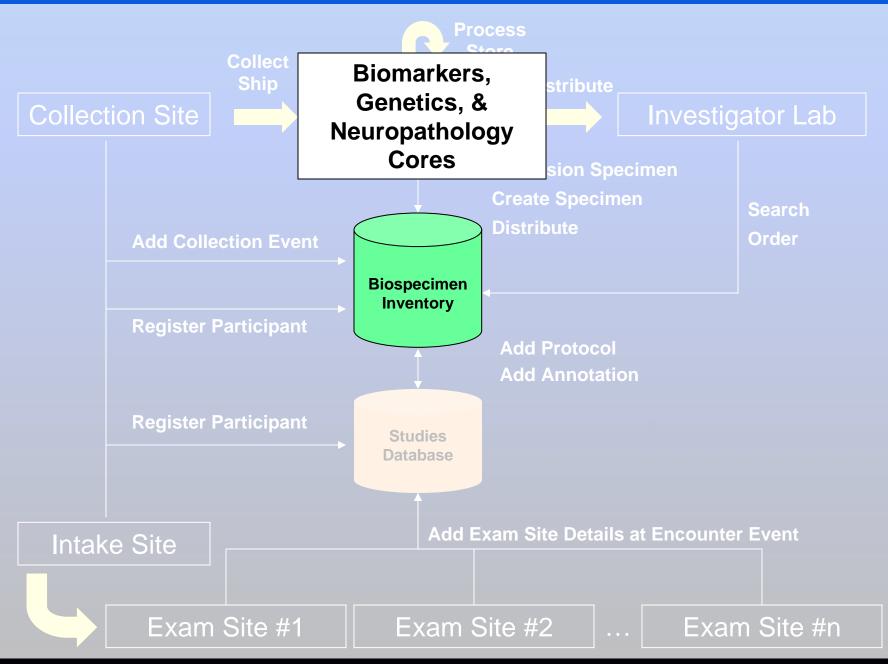
ClinPortal: Participant Registration

HOME ADMINISTRATIVE DATA DATA ENTRY	REPORT SEARCH	Si	ign Out
Clinical Study:			^
Neuro Muscular Genetics	* indicates a required field	Participant	
Participant (Protocol ID): Register New	Social Security Number (SSN)	demographics page	
N/A (01)		Last First	
	Participant		
	Birth Date		
	Vital Status	O Alive O Dead ③ Unknown O Unspecified	
=	Death Date		
Event Details for N/A (01)	Gender	○ Female ○ Male ○ Unknown ④ Unspecified	
One in the second	Sex Genotype	Unknown	=
Genetic Testing Sample management	Race	Native Hawaiian or Other Pacific Islander Not Reported Not Specified Unknown	
Patient Data Olinical Eval	Ethnicity	Unknown	
Followup Visit:Sep-18-2008	* Activity Status	Active	
Entry-1	MEDICAL IDENTIFIER(S)	Add More Delete	
Clinical Eval	Source	Medical Record Number Delete?	
	Select 💌		
Encounter events	Participant Registration(s)	Add More Delete	_
and annotations	Clinical Study	Participant Registration Activity Status Consent Delete? ID Date	
		01 09-16-2008 Active 💙 None Defined	~
CONTACT US PRIVACY NOTICE DISCL	AIMER ACCESSIBILITY R	EPORT PROBLEMS	

ClinPortal: Encounter Event and Data Entry

HOME ADMINISTRATIVE DATA DATA ENTRY	REPORT SEARCH	Sign Ou
Clinical Studv:	Primary Diagnosis	
Neuro Muscular Genetics	Diagnosis	Data entry form(s)
Participant (Protocol ID): Register New		Select
N/A (01)	Other Primary	
	Diagnosis Year of Onset	
	Inheritance Pattern	
		Select 💌
	Medical History	
	Medical Condition	
Event Details for N/A (01)	Delete	Add More
	Medication History	
One in the second	Medication	Dose Dose Unit Comments
Entry-1	Delete	Add More
Genetic Testing	Social History	
Sample management	Status	t \odot 1 - unknown \bigcirc 2 - employed \bigcirc 3 - unemployed \bigcirc 4 - retired
Patient Data	Current Job	
Clinical Eval	Longest Held Job	
🖃 📵 Followup Visit:Sep-18-2008	Highest Education	Select
Entry-1	Level	Select 💌
Clinical Eval	Smoking History	
	Packs Per Day	0
	Years Smoked	0
Encounter events	Currently Smoking	I - unknown O2 - currently smoking O3 - not currently smoking
and annotations	Alcohol Consumptio	
	Drinks per Week	0
CONTACT US PRIVACY NOTICE DISCI	LAIMER ACCESSIBIL	

Workflow of the WU ADRC



Tissue Suite

Comprehensive biospecimen informatics system

- Tissue bank functions
 - Protocol Management
 - Inventory Tracking
 - Quality Assurance / Quality Control Parameters

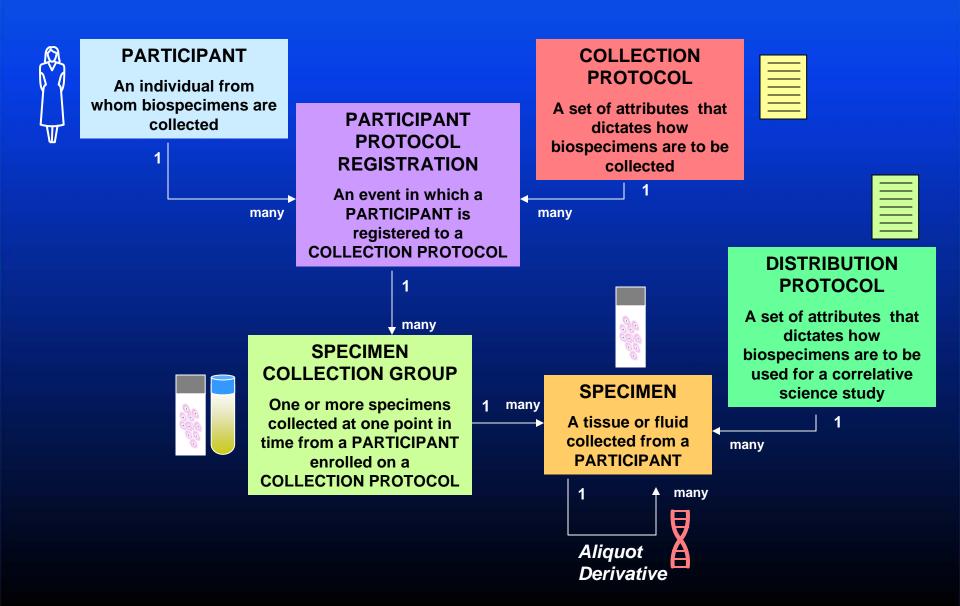
Annotation Features

- Concept-coded surgical pathology reports
- Discrete Clinical and Pathology Attributes

Researcher functions

- Graphical query interface
- Biospecimen ordering system

Tissue Suite Concepts



Tissue Suite: Participant Registration

	DATA SEARCH SUMMAR	Y HELP	Sign Out
Collection Protocol: Complicated BRCA	Add Participant Social Security Number	666 - 77 - 8888	Participant
Participant (Protocol ID): Register New	(SSN)	Last First Middle	demographics page
Click to register new Participant	Name	Noboby Nancy N	
	Birth Date	08-16-1945 (MM-DD-YYYY or MM/DD/YYYY)	
	Vital Status	O Alive ○ Dead ○ Unknown ○ Unspecified	
	Death Date	[MM-DD-YYYY or MM/DD/YYYY]	
Specimen Details for	Gender	● Female Gender ○ Male Gender ○ Unknown ○ Uns	pecified
	Sex Genotype	Unknown	
	Race	Native Hawaiian or Other Pacific Islander	
	Ethnicity	Unknown	K
	Medical Identifier(s)		Add More Delete
	Source	Medical Record Number Delete 2	
	Select 💙		P registration page
	Participant Registrat	iion(s)	Add More Delete
	Collection Protocol	Participant Protocol Registration Activity Sta ID Date	itus Consent Delete?
	Complicated BRCA	▼ 08-9999 02-15-2008 Active	Enter Response
			~
CONTACT US PRIVACY NOTICE DISCL	AIMER ACCESSIBILITY	REPORT PROBLEMS	

Tissue Suite: Add Specimen Collection Group

	ATA SEARCH SUMMARY HELP		Sign Out
Collection Protocol:	Edit Specimen Collection Group View Surgical Patholo	ogy Report View Annotation Consents	^
Complicated BRCA v			
Participant (Protocol ID): Register New	* Collection Protocol Title Complie	cated BRCA	
Noboby , Nancy (08-9999)	* Participant Name (Protocol ID) Noboby	/, Hancy(08-9999)	
	* Collection Site	Calendar clock	
Specimen Details for Noboby , Nancy (08-9999	* Specimen Group Name		
🖃 (0]T1.0: Pre-RX Biopsy: 02-16-2008	* Study Calendar Event Point	offset	
S1044	Offset		
S 1045	* Clinical Diagnosis Not Spe	cified	
⊡ ⊚1046			
E S1047	* Clinical Status Pre-The	rapy	=
©1047_1	Medical Record Number Selec	ct 💌	
©1047_2	Surgical pathology number		
© 1047_5	Comments	Collection event	
□ ①T14.0: Operative 02-29-2008	* Activity Status	(SCG) status	
S 1041	* Collection Status	V	
E §1042	Collected Event Pending	eved Event	
E S1043	Collector Admin, Admin Overdue	-Partially Complete	
Creation of all	Overldde		
expected specimens,	Completion Completion	е 02-24-2008 (ММ-DD-Y)	
derivatives, and	r lime 22 r Hr 49 Complete	e-Late 22 Hr 49	Min
	* Procedure Not Specified Not Colle		
aliquots based on CP	* Container Not Specified		
definition	Comments	Comments	

Tissue Suite: Add Specimen Collection Group

Collection Protocol: Complicated BRCA		Print Labels	Label print	ing		1. Indicate		
Participant (Protocol ID): Register New						specimens	COII	ected
Noboby , Nancy (08-9999)	Sp	ecimen details	1					
=		Label	Barcode	Туре	Qty Conc	 Location Apply Fir 	rst to All	Collected?
Specimen Details for Noboby , Nancy (08-9999	۲	1046	1046	Whole Blood	10.0	Virtual		
①T1.0: Pre-RX Biopsy: 02-24-2008	0	1045	1045	Frozen Tissue	0.05	Penn Box 12 1	3 Ē=	
③ 1044	\square							
Q 1045	0	1044	1044	Frozen Tissue	0.05	Penn_Box_12 1	4 E <mark>=</mark>	
E ©1046			1					
□ S 1047	Ali	iquot Details						
③ 1047_1	Par	ent Label	Barcode	Type Q	ty Conc. L	ocation 📃 Apply First t	to All	Created?
S 1047_2								
◎ 1047_3	104	7 1047_3	1047_3	Plasma 1.0		Penn_Box_11 7 2	E= 1	
S 1047_4	404					Penn_Box_11 10 4] 🗄 🛛	
© 1047_5	3.	Pre-defined	d / editable	labels.			-]• -	
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Tissue Suite: Other Features

Search for Frozen Breast Tunor Tissue from Patients with Last Name Starting with "W"

Class	Equals	*	Tissue	Y		
Type	Equals	*	Frozen Tissue	~	1	
Tissue Site	Equals	×	Breast, NOS	~	E	
Tissue Side	Equals	*	Left	Y		
Pathological Status	Equals	~	Malignant	~	1	
Concentration	Any	~) To [ugu
Available Quantity	Any	~			To	gm
total descentions	8 mil	-	1		14. F	
M _{Rules}			Add	Edit	Delet	e Operator
Last Name St ANY	arts With W	_	_	_	_	

Administrator / Supervisor Results View

First Name :	Last Name:"					
Participant	Participant	Middle Name : Participant	Birth Date : Participant	Gender: Participant	Social Security Number Participant	Ð
Angela	Walker		02-24-1956	Female	123-45-6788	11
Sandra	Wallbig		04-14-1966	Female	123-45-6787	12
Mike	Waters		01-11-1923	Male	123-45-6789	10
Arthur	Waxman		05-16-1934	Male	123-45-6776	13
	Angola Sandra Mike Adhur	Sandra Walibig Mike Waters	Sandra Walibig Mike Waters	Sandra Walibig 04-14-1966 Mike Waters 01-11-1923	Sandra Walibig 04-14-1966 Female Mike Waters 01-11-1923 Male	Sandra Wallbig 04-14-1966 Female 123-45-6787 Mike Waters 01-11-1923 Make 123-45-6789

Scientist Results View

	First Name : Participant	Last Name Participant	Middle Name Participant	Birth Date : Participant	Gender: Participant	Social Security Number : Participant	Identifier Participant
3	**	**	**	**	Male	**	10
	**	**	**	**	Female	**	11.
1	**	**	**	**	Female	**	12
	**	**	**	**	Male	**	13

Protocol PI Scientist Results View

	First Name : Participant	Last Name : Participant	Middle Name : Participant	Birth Date : Participant	Oender: Participant	Social Security Number : Participant	Identifier : Participant
0	88	**	**	**	Male	**	10
	**	**	**	**	Female	**	11
0	\$\$	**	**	**	Female	**	12
	**	**	**	**	Male	**	13
0	Wendy	Willing		09-15-1977	Female	123-45-7777	14

Check All

Progress to Date

<u>Neuropathology Core</u> migrated to Tissue Suite for

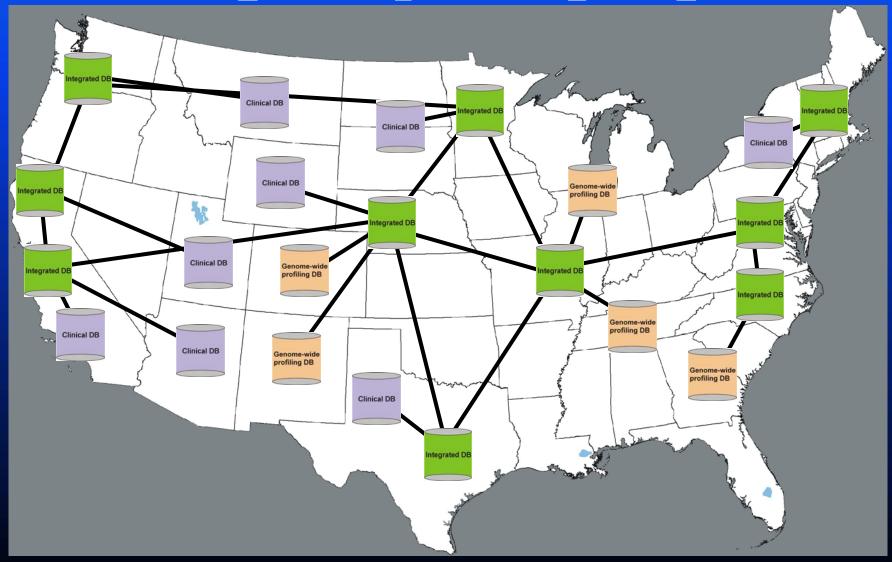
prospective biospecimen collection: Creating forms for

144	scalarianiology						
	ls ischemic pathology present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Is hemorrhagic pathology present?	🔘 1 Yes	🔾 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Is vascular pathology present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Are one or more large artery cerebral infarcts present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Are one or more cortical microinfarcts (including granular atrophy) present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Are one or more lacunes (small artery infarcts and/or hemorrhages) present?	🔘 1 Yes	◯ 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Are single or multiple hemorrhages present?	🔘 1 Yes	🔵 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Is subcortical arteriosclerotic leukoencephalopathy present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Is cortical laminar necrosis present?	🔘 1 Yes	🔾 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	ls medial temporal lobe sclerosis (including hippocampal sclerosis) present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	Is atherosclerotic vascular pathology (of the circle of Willis) present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	l 🔘 4 Missi	ng/unknown	
	ls arteriosclerosis (small parenchymal arteriolar disease) present?	🔘 1 Yes	🔿 2 No	◯ 3 Not assessed	I 🔘 4 Missi	ng/unknown	
	Is amyloid angiopathy present?	🔘 1 None	🔵 2 Mil	d 🔘 3 Moderat	◯4 Sever	◯ 5 Not assessed	◯ 6 Missing/unknown
	Is another type of angiopathy (e.g.	🔘 1 None	🔵 2 Mil	d 🔘 3 Moderat	◯4 Sever	◯ 5 Not assessed	◯ 6 Missing/unknown
	Is there other pathology related to ischemic or vascular disease not previously specified present?	🔘 1 None	🔿 2 Mil	d 🔘 3 Moderat	◯4 Sever	◯ 5 Not assessed	○ 6 Missing/unknown

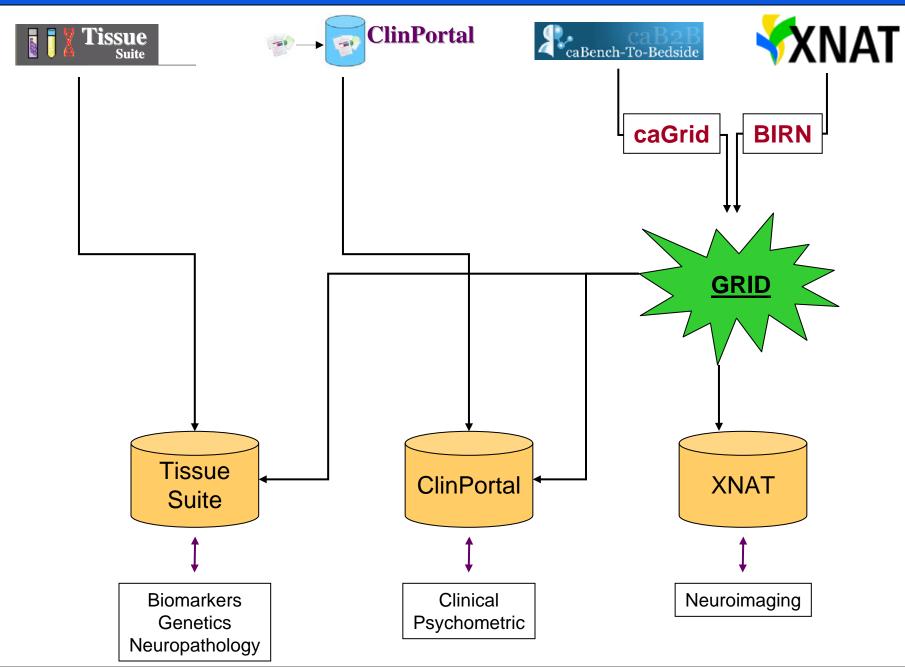
<u>Neuroimaging Core</u> integration by late 2009

Institution to Global Integration

caBIG: <u>cancer Biomedical Informatics Grid</u> CTSA: <u>Clinical and Translational Science Award</u>



Summary: ADRC Data Integration and Sharing



Acknowledgments

On-site Team

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