The Wisconsin Alzheimer's Disease Research Center's On-Line Recruitment Registry *"Reggie"*

Carey Gleason, PhD
Center Administrator

Acknowledgments

Data Core

- Nevin Olson
- Tom Mish
- Dave Towers
- Preethy Kaprakattu
- Dave Tolmie
- Maritza Dowling
- Vince Streif
- Neeraja Deshpande

Clinical Core

- Kari Paterson
- Mirriam Rosen
- Jackie Lee
- Jane Sachs
- Amy Hawley
- Hanna Blazel

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Starting Point

Multiple Recruitment databases (e.g., Excel; Access; SPSS)

- Every contact = separate record
- No standardization (e.g., DOB)
- No report or search capabilities
- No shared access
  - More than one coordinator contacting a subject
  - Unable to field some calls

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Challenges

- Protocol-Specific Screening
  - Different populations
  - Divergent minimum requirements
- IRB/Consent to retain information
  - Permission to retain sensitive information in database (e.g., diagnosis)
  - Capacity assessments?
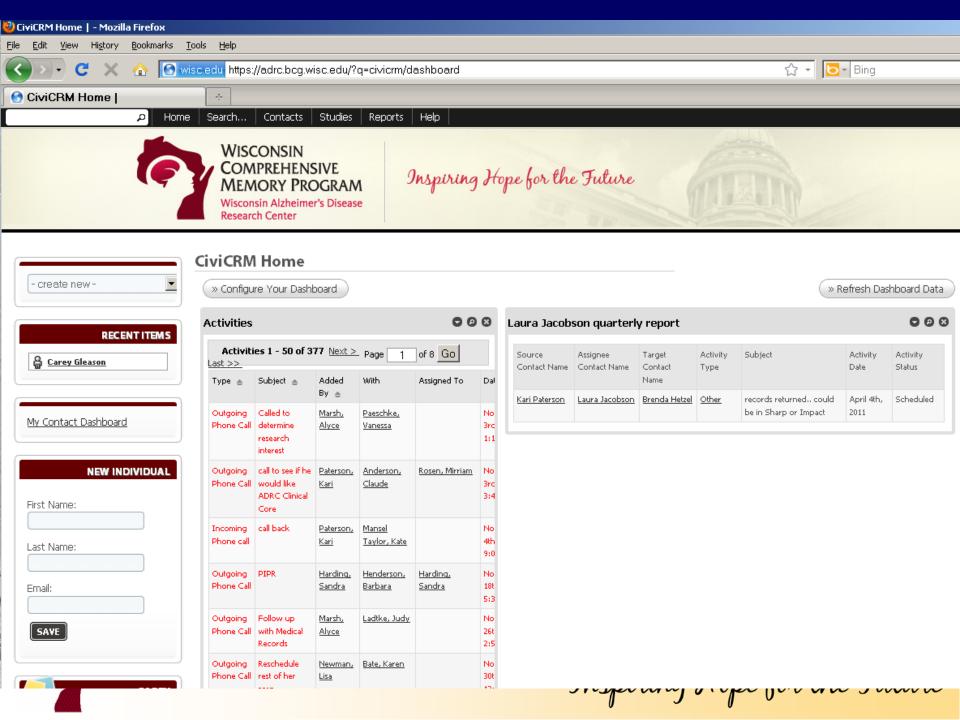 - Wanted to keep some information on ALL Contacts

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Getting Started

- Key Distinction
  - Recruitment data are not study data
    - Need Contact Management System
- Key Steps
  - Series of 12 meetings
    - Identified exact variables
    - Understood how database should be built by knowing how we will use it

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Home   Search...   Contacts   Studies   Reports   Help

WISCONSIN COMPREHENSIVE MEMORY PROGRAM
Wisconsin Alzheimer's Disease Research Center

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CiviCRM Home

» Configure Your Dashboard

» Refresh Dashboard Data

- create new -

RECENT ITEMS

Carey Gleason

My Contact Dashboard

NEW INDIVIDUAL

First Name:

Last Name:

Email:

SAVE

Activities

Activities 1 - 50 of 377 Next > Page [1] of 8 Go
Last >>

Type	Subject	Added By	With	Assigned To	Dal
Outgoing Phone Call	Called to determine research interest	Marsh, Alyce	Paeschke, Vanessa		No 3rc 1:1
Outgoing Phone Call	call to see if he would like ADRC Clinical Core	Paterson, Kari	Anderson, Claude	Rosen, Mirriam	No 3rc 3:4
Incoming Phone call	call back	Paterson, Kari	Mansel Taylor, Kate		No 4th 9:0
Outgoing Phone Call	PIPR	Harding, Sandra	Henderson, Barbara	Harding, Sandra	No 18t 5:3
Outgoing Phone Call	Follow up with Medical Records	Marsh, Alyce	Ladtke, Judy		No 26t 2:5
Outgoing Phone Call	Reschedule rest of her	Newman, Lisa	Bate, Karen		No 30t

Laura Jacobson quarterly report

Source Contact Name	Assignee Contact Name	Target Contact Name	Activity Type	Subject	Activity Date	Activity Status
Kari Paterson	Laura Jacobson	Brenda Hetzel	Other	records returned.. could be in Sharp or Impact	April 4th, 2011	Scheduled

New WCMP Contact
New Mailing List Contact
New WCMP Staff
New Study
New Activity
New Group
Manage Groups

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AM
ease

New WCMP Contact

 Screening Script (PDF)

[SAVE] [SAVE AND NEW] [CANCEL]

▼ **WCMP Contact Form**

Today's Date: [*] [_____] 🗓 (clear)

1) Contact: [*]

○ In person ○ Phone Call ○ Email ○ Postal Mail ○ Unknown (unselect)

2) What is the main reason(s) for contacting the WCMP? (check all that apply)

☐ Interested in research for self   ☐ Interested in research for loved one

☐ Concerned about memory (self)   ☐ Concerned about memory of a loved one

☐ Want more information about [_____]

☐ Other -- please specify: [_____]

3) Potential Participant: [*]

○ Self ○ Loved One ○ Both ○ Unknown (unselect)

If you are contacting us about someone other than yourself, please answer the questions as they apply to the potential subject.

4) Does the potential Study Participant have a DIAGNOSED memory disorder? [*]
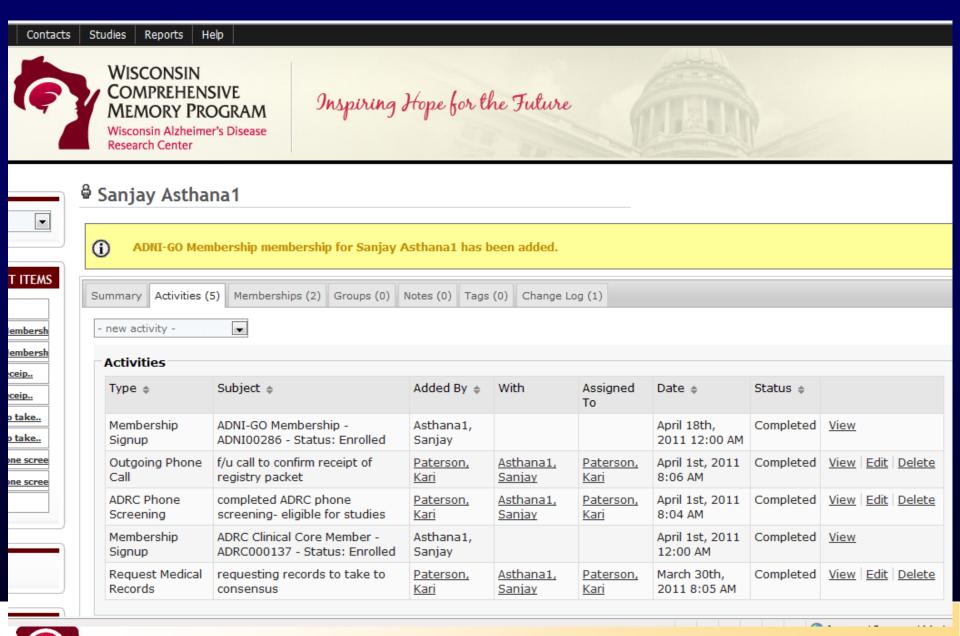
○ Yes ○ No ◉ Unknown (unselect)

T ITEMS

IVIDUAL

CAREY

ure

WCMP Participant ICF Outcome

a1) Outcome of first contact ▪

⊙ Eligible to continue
○ Not eligible -- Age
○ Not eligible -- Medical
○ Not eligible -- Other [   ]

(unselect)

a2) Follow-up Required ○Yes ○No   (unselect)

a3) Interviewer (Last Name, First Name) [   ]

Obtain Consent (Must be eligible)

a4) Verbal consent read

○Yes ○No   (unselect)

a5) Participant verbal consent received

○ Yes
○ Refused consent -- Time Constraint
○ Refused consent -- Not Interested
○ Refused consent -- Reason Unknown
○ Refused consent -- Other [   ]

(unselect)

Personal Data Form (Must have consent)

SAVE   SAVE AND NEW   CANCEL

Future

Contacts | Studies | Reports | Help

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Wisconsin Alzheimer's Disease Research Center

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🔒 Sanjay Asthana1

ⓘ **ADNI-GO Membership membership for Sanjay Asthana1 has been added.**

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| Summary | Activities (5) | Memberships (2) | Groups (0) | Notes (0) | Tags (0) | Change Log (1) |

- new activity -

Activities

Type ⇕	Subject ⇕	Added By ⇕	With	Assigned To	Date ⇕	Status ⇕	
Membership Signup	ADNI-GO Membership - ADNI00286 - Status: Enrolled	Asthana1, Sanjay			April 18th, 2011 12:00 AM	Completed	View
Outgoing Phone Call	f/u call to confirm receipt of registry packet	Paterson, Kari	Asthana1, Sanjay	Paterson, Kari	April 1st, 2011 8:06 AM	Completed	View | Edit | Delete
ADRC Phone Screening	completed ADRC phone screening- eligible for studies	Paterson, Kari	Asthana1, Sanjay	Paterson, Kari	April 1st, 2011 8:04 AM	Completed	View | Edit | Delete
Membership Signup	ADRC Clinical Core Member - ADRC000137 - Status: Enrolled	Asthana1, Sanjay			April 1st, 2011 12:00 AM	Completed	View
Request Medical Records	requesting records to take to consensus	Paterson, Kari	Asthana1, Sanjay	Paterson, Kari	March 30th, 2011 8:05 AM	Completed	View | Edit | Delete

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Activity Dashlet

Type	Subject	Added By	With	Assigned To	Date	Status			
Annual Year 2 Visit	last yr was phone interview only, pls see if they can come in for appt	Paterson, Kari	Smith, Mary	Rosen, Mirriam; Cychosz, Jorna	March 7th, 2012 3:36 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Cleary, Caitlin	Smith147, Linda	Cleary, Caitlin	December 28th, 2011 2:42 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Lee, Lisa	Flanders161, Peggy	Cleary, Caitlin	June 1st, 2011 9:30 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Paterson, Kari	Flanders153, Victoria	Rosen, Mirriam	May 9th, 2011 10:42 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Marsh, Alyce	Jenkins136, Kelly	Harding, Sandra	April 16th, 2011 2:27 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Harding, Sandra	Yee99, Kathy	Harding, Sandra	April 12th, 2011 12:16 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Harding, Sandra	Yee165, Jerry	Harding, Sandra	April 11th, 2011 11:50 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Cleary, Caitlin	Yee198, Gerry		April 11th, 2011 10:43 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Cychosz, Jorna	Flanders198, Riley	Zeisse, Madeline	April 7th, 2011 12:42 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Harding, Sandra	Charles180, Kelly	Rosen, Mirriam	April 4th, 2011 12:03 PM	Scheduled	View	Edit	Delete
Send Registry Packet		Horn, Kelly	Davis, Donald	Horn, Kelly	March 23rd, 2011 10:17 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	call	Horn, Kelly	Davis, Donald	Horn, Kelly	March 23rd, 2011 10:13 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Harding, Sandra	Evitts, Jim	Harding, Sandra	March 22nd, 2011 3:51 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Subject for Outgoing Phone Call	Harding, Sandra	Beatty, Ellouise	Harding, Sandra	March 21st, 2011 4:11 PM	Scheduled	View	Edit	Delete
Outgoing Phone Call	Call after sending red folder	Hawley, Amy	Lee, Annabell	Hawley, Amy	March 21st, 2011 11:37 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	after letter sent out	Paterson, Kari	Davis, Elton	Harper, Enjoli	March 21st, 2011 10:17 AM	Scheduled	View	Edit	Delete
Outgoing Phone Call	after letter sent out	Grady, Christine	Smith, Sally	Grady, Christine	March 21st, 2011	Scheduled	View	Edit	Delete

Implementation Challenges

- Transferring data
  - Transferred over 2000 contacts
  - Had to identify what data fields mapped to new variable names
  - Duplicates
- Training
  - Determine minimum standards
    - How/what to record, etc
  - Needs periodic refresher courses

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Sample Reports

- Number enrolled in given period of time

Home | Search... | Contacts | Studies | Reports | Help

Reports Listing
Create Reports from Templates
Study Membership Report (Detail)
Study Membership Report (Lapsed)

- create new -

RECENT ITEMS

Kari Paterson

My Contact Dashboard

NEW INDIVIDUAL

First Name:

Last Name:

Email:

SAVE

KARA

- REGGIE
- Help Page
- Consent Form
- Groups
- My Unread
- My account
- Recent posts
- Administer
- Log out

CiviMember

Membership Summary ?

Members by Type	March — New/Renew (Last Month)	April — New/Renew (MTD)	2011 — New/Renew (YTD)	Current #
ADRC Clinical Core Member	3	1	14	81
SHARP Member	1	0	9	56
Eli Lilly Member	0	0	0	6
PREDICT Member	3	0	8	62
Falls Member	0	0	7	27
Merit 220 Member	0	0	0	86
PIPR Member	1	0	1	26
SEAIRA Member	1	0	3	12
VA Cooperative Member	1	0	1	13
IGIV Member	0	0	1	7
ELAN Member	0	0	0	0
TBIVA Member	0	0	0	0
WMAD Member	0	0	0	1
Eli Lilly Open Label Extension Member	1	0	1	1
Elan 301 Member	0	0	0	2
Elan Open Label Extension Member	0	0	0	0
Elan 3001 Screen fails from 301 Member	0	0	0	0
Active Recruitment Process Member	0	0	0	3
ADRC IMPACT Member	2	0	5	46
Brain Donor Program Member	0	0	0	127
ADNI Membership	0	0	0	4
ADNI-GO Membership	1	0	1	8

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Sample Reports

- Number enrolled in given period of time
- Number enrolled in Clinical Core AND another study
- Personnel recruitment efforts
- Success of recruitment efforts
  - Number of people referred by Alzheimer's Association
  - Number of people calling in response to an ad

How to make this happen

- Key Personnel
  - Medical informatics specialist or software engineer
  - Staff to direct/organize development
  - Team member familiar with recruitment
- Resources
  - Low end: freeware + some programming hours
  - High end: build a program

Smart People to Talk to

In alphabetical order:
- Tom Mish: mish@biostat.wisc.edu
- Nevin Olson: olson@biostat.wisc.edu